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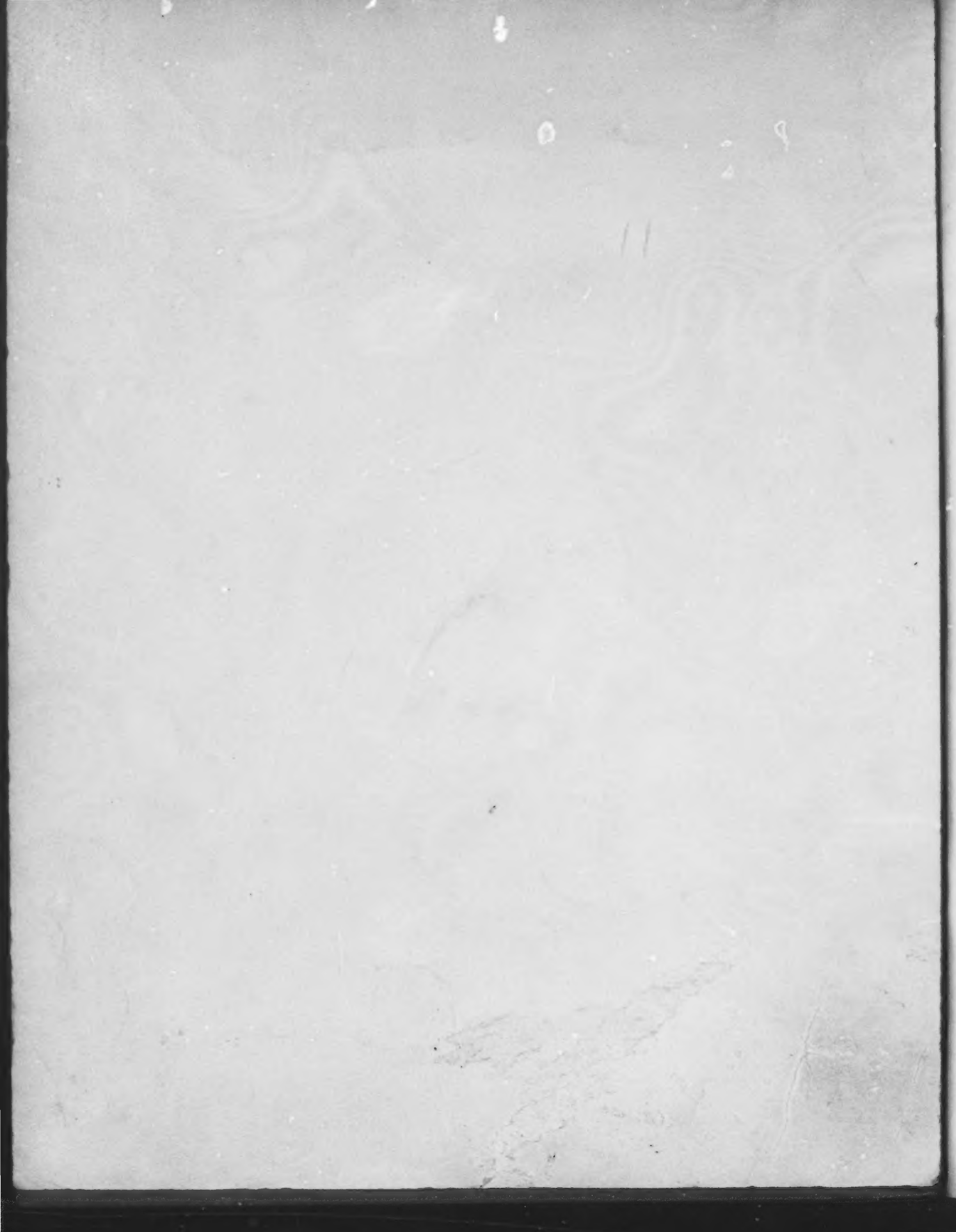
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STATE LAWS AND REGULATIONS ON GENETIC DISORDERS



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES • Public Health Service • Health Services Administration • Bureau of Community Health Services

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FOREWORD

This publication was prepared by the Laws Committee of the American Society of Human Genetics (ASHG) and published by the National Center for Human Genome Research, Public Health Service, U.S. Department of Health, Education, and Welfare, in 1977. The primary publication has been published by the American Society of Human Genetics (ASHG) and the National Center for Human Genome Research. The Laws Committee has been established to provide information on laws and regulations which pertain to genetic disorders. The Laws Committee has been established to provide information on laws and regulations which pertain to genetic disorders. The Laws Committee has been established to provide information on laws and regulations which pertain to genetic disorders.

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July 1980

The assistance and cooperation of the members and staff of the American Society of Human Genetics (ASHG) and the National Center for Human Genome Research, Public Health Service, U.S. Department of Health, Education, and Welfare, in the preparation of this publication is gratefully acknowledged. The assistance and cooperation of the members and staff of the American Society of Human Genetics (ASHG) and the National Center for Human Genome Research, Public Health Service, U.S. Department of Health, Education, and Welfare, in the preparation of this publication is gratefully acknowledged.

All laws, regulations, and regulations are printed in unannotated form. The Laws Committee of the American Society of Human Genetics (ASHG) has been established to provide information on laws and regulations which pertain to genetic disorders. The Laws Committee has been established to provide information on laws and regulations which pertain to genetic disorders. The Laws Committee has been established to provide information on laws and regulations which pertain to genetic disorders.

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U.S. Department of Health and Human Services
Public Health Service
Health Services Administration
Bureau of Community Health Services
Genetic Disease Services Branch
National Clearinghouse for Human Genetic Diseases

STATE LAWS AND REGULATIONS ON GENETIC DISORDERS

July 1980

1. Purpose: To provide information on state laws and regulations regarding genetic disorders.

2. Scope: This document covers the following states: California, New York, and Texas.

3. Definitions: The following definitions apply to the information provided in this document:

- Genetic disorder: A disease or condition caused by a change in the DNA sequence.
- Carrier: A person who has a copy of a gene for a genetic disorder but does not have the disorder.
- Progeny: The offspring of a couple.

FOREWORD

This publication was preceded by *State Laws Pertaining to Phenylketonuria as of November 1970* published by the Maternal and Child Health Service, Public Health Service, U.S. Department of Health, Education, and Welfare in 1971. The present publication has been expanded to include summaries of those state and territorial laws and regulations which pertain to human genetic disorders. These summaries are presented here for informational purposes. Although great care has been exhibited in the preparation of the summaries, the laws and regulations themselves should be consulted and reviewed if there is a question concerning the precise wording and context. The listing of a law or a set of regulations does not imply recommendation or approval by the U.S. Government. Conversely, the omission of a state law or regulation is in no way to be construed as a negative recommendation or disapproval.

In the preparation of this booklet, the directors of the Maternal and Child Health and Crippled Children's Services in each of the state departments of health were contacted to obtain copies of the laws and regulations on genetic disorders. The Legislative Information Office for each state was consulted concerning statute citations and legislative bill status. Only those laws or regulations enacted or promulgated as of July 1980 have been included. The material has not been selectively screened; the material submitted by the state directors was the sole determining factor for inclusion.

To aid the user, the state directors of Maternal and Child Health and Crippled Children's Services and the Legislative Information Offices have been included in Appendices B and C.

The assistance and cooperation of the directors and staff of the individual Maternal and Child Health and Crippled Children's Services programs are appreciated. The respective Legislative Information Offices, the Cystic Fibrosis Foundation, and the National Hemophilia Foundation are also acknowledged for their assistance in the preparation of this document. Additionally, appreciation is extended to Philip Reilly.

As new laws, amendments, or regulations are enacted or promulgated, the project director would appreciate receiving a copy of these materials. Comments and suggestions are welcomed and should be submitted to:

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FOREWORD

This publication was prepared by the U.S. Government Printing Office as a supplement to the 1970 publication by the National and Child Health Survey, U.S. Department of Health, Education and Welfare. The present publication has been expanded to include information on the status of state and federal laws and regulations which relate to birth defects. This information is presented here for informational purposes. Although it is not included in the publication of the summary, the laws and regulations themselves would be contained in a list of regulations from the state and federal government and would be listed in a list of regulations from the state and federal government. However, the U.S. Government Printing Office, the publisher of this publication, is in no way to be construed as a negative recommendation of legislation.

In the preparation of this book, the efforts of the National and Child Health Survey, U.S. Department of Health, Education and Welfare, are gratefully acknowledged. The National and Child Health Survey, U.S. Department of Health, Education and Welfare, is the source of the data on the status of state and federal laws and regulations on birth defects. The Legislative Information Office for each state was consulted concerning state and legislative bills. Only those laws or regulations enacted or promulgated as of July 1980 have been included. The material has been selectively screened; the material submitted by the state director was the sole determining factor for inclusion.

To aid the user, the state directors of National and Child Health Survey, U.S. Department of Health, Education and Welfare, and the Legislative Information Office have been included in Appendices B and C.

The assistance and cooperation of the director and staff of the National and Child Health Survey, U.S. Department of Health, Education and Welfare, are appreciated. The respective Legislative Information Office, the Cystic Fibrosis Foundation, and the National Hemophilia Foundation are also acknowledged for their assistance in the preparation of this document. Additionally, appreciation is extended to Philip R. Kelly.

A new law, amendment, or regulation are enacted or promulgated, the project director would appreciate receiving a copy of these materials. Comments and suggestions are welcomed and should be submitted to:

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INTRODUCTION

Since the development in the early 1960s of the Guthrie test, which allowed for high quality and inexpensive mass screening of newborns for the detection of phenylketonuria (PKU), and the enactment in 1963 by the State of Massachusetts of a law mandating the screening of all newborns for PKU, popular concern with legislation on genetic screening has continued.

This publication is a compendium of statutes and regulations on genetic disorders promulgated by the individual states and the District of Columbia. At the present time neither the Commonwealth of Puerto Rico nor the U.S. territories of American Samoa, Guam, Mariana Islands, Trust Territory of the Pacific Islands, nor the Virgin Islands have enacted any laws or regulations on genetic disorders.

The laws and regulations reflect a great deal of diversity and variety. This is particularly discernible in the newborn screening statutes which indicate a derivation from no single legislative model. However, it is possible to identify in some cases all or part of one state statute which has been borrowed by others.

Beginning in the early 1970s there has been increased legislative activity. This has been due in part to the advent of new infant screening capabilities, in particular, the test for hypothyroidism. There has also been a widespread recognition of the need to refine PKU screening laws which were rapidly passed in the 1960s as well as to amend the sickle cell legislation of the early 1970s. These amendments and regulations have addressed some but not all of the problems identified with mass screening: voluntary participation; public consultation before adoption of a screening program; informed consent; consideration of economic, social, and ethical issues; counseling and educational services; confidentiality of test results and their availability to the person tested; treatment and follow-up of individuals screened positive; and quality control of the tests.

As of October 1980, all of the states, including the District of Columbia, will probably have newborn screening programs. Of these, 48 have legislative statutes giving authority for the programs. The remaining three have regulations promulgated by the respective Departments of Health. It should be noted that the effectiveness of a screening program is not directly related to legislative status: programs are and have been successfully organized without legislation.

Almost all of the states have expanded newborn screening to cover disorders other than PKU. In many states this was and is possible due to the broadly worded laws mandating testing for PKU "and other causes of mental retardation." Other states have amended or enacted legislation allowing for the expansion of the scope of the programs without additional legislation. Some states have enacted special laws as necessary to change the screening program. In Appendix A, a tabular survey is shown of current newborn programs listing the disorders screened.

The publication is divided into two sections: Laws and Regulations and Appendices. The laws and regulations are organized under the particular state or territory which has enacted them. The states are listed alphabetically followed by the territories. For each, an introductory summary is given followed by sections on Newborn Screening Statutes, Administrative Regulations (i.e., Newborn Screening), and other Relevant Laws or Regulations.

Appendices consist of a survey of newborn screening programs, maternal and child health and crippled children's service directors, and state legislative information offices.

For additional information the reader may want to refer to the following:

Childs, B. et al. 1976. Tay-Sachs screening: social and psychological impact. *Amer. J. Hum. Genet.* 28:550-58.

Committee for the Study of Inborn Errors of Metabolism. 1975. *Genetic screening programs, principles, and research*. Washington: National Academy of Sciences - National Research Council, Assembly of Life Sciences (NTIS PB-245-086).

Cystic Fibrosis Foundation. 1979. *Over - 21 survey*. Rockville, MD.

Dussault, J.H. et al. 1975. Preliminary report on a mass screening program for neonatal hypothyroidism. *J. Pediat.* 86:670-74.

Klein, A.H., Agustin, A.V., and Foley, T.P. 1974. Successful laboratory screening for congenital hypothyroidism. *Lancet* 2:97-99.

Milunsky, A. and Annas, G., eds. 1976. *Genetics and the law*. New York: Plenum Press.

Milunsky, A. and Annes, G., eds. 1980. *Genetics and the law II*. New York: Plenum Press.

National Hemophilia Foundation. 1979. *State and Federal resources guide for hemophiliacs*. rev. ed. New York.

Powlledge, T.M. 1978. Genetic Screening. In *Encyclopedia of Bioethics*, Vol. 2. Reich, W.T., ed., pp. 567-72. New York: Free Press.

Reilly, P.R. 1977. *Genetics, law, and social policy*. Cambridge: Harvard University Press.

Reilly, P.R. 1978. Government support of genetic services. *Social Biol.* 25(1):23-32.

Swazey, J. 1971. Phenylketonuria: A case study in biomedical legislation. *J. Urban Law* 48:853-931.

The State of Alabama has one statute concerning the prevention of the deleterious effects of genetic diseases. This law requires that all infants be tested for phenylketonuria (PKU) and hypothyroidism.

Newborn Screening Statutes

Section 22-20-3 of the Code of Alabama assigns the administrative officer or other person in charge of each institution caring for newborn infants, the physician attending a newborn, or the person assisting the birth of a child not attended by a physician, the responsibility for ensuring that every child in his care be tested for PKU and hypothyroidism. The proper methods of testing and recording the results of the tests shall be prescribed by the State Board of Health.

The State Board of Health shall enact rules and regulations as it deems necessary for the provision of care and treatment, including diet therapies, of those infants with positive tests. The board may institute any other rules or regulations that may be needed to properly implement this statute.

Any child whose parents object to the provisions of the statute on religious grounds will be exempt from the tests.

Administrative Regulations

There are no formal regulations accompanying the newborn screening statutes.

Other Relevant Laws or Regulations

The Alabama Perinatal Health Act, 80-761 of the Acts of 1980, provides for the establishment of perinatal care programs aimed at reducing infant mortality and handicapping conditions. The administration of this program shall be through a system providing quality perinatal care in the closest proximity to the patient's residence based on the levels-of-care concept of regionalization. The closest cooperation between various state and local agencies and private health care services shall be a goal. This program shall include primary care, hospital and prenatal; secondary and tertiary levels of care, both on an inpatient and outpatient basis; transportation to the facilities where medical services and evaluation of infants through the first year of life are received; and educational programs on adequate perinatal care.

ALASKA

In 1967, Alaska enacted a statute concerning the screening of infants for phenylketonuria (PKU) and inherited disorders which lead to mental retardation and physical handicapping. In addition to PKU, Alaska presently screens for hypothyroidism, galactosemia, tyrosinemia, homocystinuria, maple syrup urine disease, and Hartnup's disease.

Newborn Screening Statutes

Alaska Statute Section 18.15.200, "Screening Infants for Phenylketonuria," requires the physician or nurse who first visits the child to test for PKU and other inherited disorders that lead to mental retardation and physical handicaps. The Department of Health and Social Services is empowered to regulate the methods of testing used and the times of testing, and is required to provide the necessary laboratory tests and materials. A positive test is reported by the testing laboratory to the physician and the department. The department then initiates further tests and if the diagnosis is confirmed, it is reported to the physician and the department. The department shall also provide treatment. This statute has determined that a licensed physician or nurse who violates this decree is guilty of a misdemeanor. He or she may, upon conviction, be punished by a fine of up to \$500. However, if the newborn's parent or guardian objects to the test, the physician or nurse shall not be held in violation.

Administrative Regulations

A broader based regulation given authority by the statute, entitled "Screening for Metabolic Disorders," was passed in 1978. Alaska Administrative Codes 27.510 to 27.530 provide a description of standards to be employed in the detection of metabolic disorders. The Department of Health and Social Services supplies laboratory services for the screening of these disorders. Responsibility for the submission of the specimens for testing rests with the physician or nurse, though they do not necessarily have to perform the actual collection of the sample.

ARIZONA

The State of Arizona has two statutes, which were recently amended effective July 31, 1980, relating to genetic diseases. Arizona Revised Statutes 36-797.41 through 36-797.43 deal with sickle cell anemia. Arizona Revised Statute 36-694 concerns blood and metabolic tests at birth. Arizona Regulations 9-14-515 were designed pursuant to the statutory authority granted in Section 36-694.B. Arizona has also enacted a law proscribing unfair discrimination against hemophiliacs relating to certain conditions in insurance policies.

Newborn Screening Statutes

Arizona Revised Statutes Section 36-694, "Report of Blood and Metabolic Tests on Birth Certificate," was amended to include testing for metabolic disorders. The tests must be performed or caused to be performed by the attending physician or other person required to issue a report on the birth. These tests are specifically indicated by rules and regulations designed by the Department of Health Services and consistent with the recommendations of the Metabolic Screening Committee. This committee, composed of the director of the Department of Health Services and five physicians, shall review annually, or more frequently if necessary, each specified test.

Administrative Regulations

The director of the Department of Health Services, as required by A.R.S. 36-694, has adopted Regulations R9-14-511 through R9-14-515. These regulations endeavor to ensure that every newborn, with the consent of parent or guardian, shall be screened for metabolic disorders. It is the aim of the tests to detect the disorders and provide early treatment in the hope of preventing or substantially ameliorating mental retardation. The regulations prescribe the testing of newborns for phenylketonuria (PKU), galactosemia, and hypothyroidism. Additionally, homocystinuria and maple syrup urine disease are screened in newborns, but they have not been written into the regulations. The physician, nurse midwife, or licensed midwife in attendance at the birth is responsible for ordering the tests. The chief of the institution, or his designated representative, confirms that the medical record of the infant indicates that the metabolic disorder testing was performed, or that the parent or guardian refused the tests. In the case of the birth of a child outside an institution, the physician, the nurse midwife, or the licensed midwife at the birth is responsible for seeing that the tests are performed. Objection of the child's parents to the testing for metabolic disorders must be noted in the newborn's medical record, whether or not the child was born in an institution.

Other Relevant Laws or Regulations

The purpose of Arizona Revised Statutes Sections 36-797.41 to 36-797.43 is to aid in the early detection of sickle cell anemia and related disorders. It is the responsibility of the State Department of Health to designate tests and regulations in accordance with accepted medical practice to attain this goal. The department may, through the Crippled Children's Services, develop and maintain, either directly or by contracting with public or private providers, programs for the diagnosis, care, and treatment of children suffering from sickle cell anemia. Testing for this disease may be administered at the following times: upon first enrollment of a child in primary school; upon first enrollment in junior or senior high school for the child who was not tested in primary school in the state; upon application of a couple for a marriage license; and during pregnancy. In addition, the State Department of Health may require testing for sickle cell anemia and related blood diseases for any identifiable section of the population that it determines is more likely to develop the disease than the remainder of the population. Any test performed must be done with the consent of the person to be tested, or if the person is a minor, with the consent of the parent or guardian.

Funding for this screening program is appropriated through the Crippled Children's Services. The parent or other responsible person, agency, or third party payor shall reimburse the department for all or part of the costs of the services rendered to a child, according to a sliding scale of rates and charges established by the department.

Section 20-448 of Arizona Revised Statutes states that no discrimination may be made between individuals of the same class, who have substantially similar insuring, risk, and exposure factors, in the rates and conditions set for any life, disability, or other insurance contract.

Additionally, no person shall institute or permit any unfair discrimination with respect to hemophiliacs in the amount of premium, policy fees or rates charged, or benefits payable for any policy or contract of disability insurance. This subsection shall not be applicable to any policy or subscription contract that provides only benefits for specific diseases or for accidental injuries or that provides only indemnity for blood transfusion services or replacement of whole blood products or derivatives.

ARKANSAS

Arkansas has one law respecting screening for genetic and metabolic diseases. In 1967, a statute was enacted that provides for the testing of infants to detect phenylketonuria (PKU) and empowers the State Board of Health to issue regulations implementing that provision. In addition, Arkansas provides voluntary screening for hypothyroidism.

Newborn Screening Statutes

Under Sections 82-625 to 82-628 of the Arkansas Statutes Annotated, the State Board of Health may, after adequate notice and hearing, propose regulations requiring that all newborn infants be tested for PKU in the manner deemed safe and effective by the board. If the board does issue such regulations, it shall require that no birth certificate may be properly submitted to the Bureau of Vital Statistics without proof that such a test has been made. In addition to prescribing the regulations implementing this law, the following duties are relegated to the board: (1) enforcing the provisions of this act; (2) furnishing copies of this act and the regulations to physicians, hospitals, or other institutions or persons determined by the regulations to be responsible for the testing; (3) researching and licensing laboratories it deems qualified to assay specimens for the presence of PKU or other metabolic defects; (4) creating, equipping, and staffing a central laboratory to receive specimens, make tests, and report findings of those tests; (5) distributing information and advice to the public concerning the nature and effects of PKU and other metabolic defects; and (6) assisting in the treatment and care of infants with these disorders.

The provisions of this law shall not apply to any child whose parent or guardian objects because the tests conflict with the tenets and customs of a recognized church or religious denomination of which the parent or guardian is a member.

The State Board of Health may enforce this statute by appropriate action for injunction in the Chancery Courts of the state.

Administrative Regulations

Formal regulations for newborn screening have not been promulgated at this time.

Other Relevant Laws or Regulations

Act 330 of the 1977 Acts of Arkansas provides for establishment of a statewide registry of all individuals with spinal cord disabilities, congenital or acquired. The registry will be maintained by the Arkansas State Spinal Cord Commission, and inclusion in the registry requires prior consent of the individual. The duties of the commission are to advise spinal cord disabled persons or their families about assistance available from the state, to refer them to appropriate divisions, departments, or agencies for rehabilitative services, and to obtain the cooperation of other state agencies.

CALIFORNIA

The State of California has promulgated an extensive program of legislation aimed at the attenuation and prevention of various genetic diseases. The Hereditary Disorders Act of the California Health and Safety Code sets forth the major premises, philosophies, and policies of the state on genetic disorders. Under this law, California has enacted statutes and established regulations governing the screening of infants for metabolic disorders, the testing of pregnant women to detect genetic disorders of the fetus, educational programs on the diseases, sickle cell screening programs, adult cystic fibrosis programs, and genetic counseling.

Newborn Screening Statutes

Article 3, Section 309 of the Hereditary Disorders Act requires the State Department of Health Services to establish a genetic disease unit that shall coordinate all programs of the department in the area of genetic disease. The genetic disease unit shall evaluate and prepare recommendations on the testing of infants for the following diseases besides phenylketonuria (PKU): galactosemia, galactokinase deficiency, homocystinuria, histidinemia, maple syrup urine disease, hypothyroidism, and tyrosinosis. Recently amended, the department shall implement tests for all infants born in California to detect PKU, galactosemia, and hypothyroidism. The department is authorized to provide laboratory facilities or to contract with any laboratory to conduct such tests. The department is required to charge for any test administered pursuant to this program, the revenue from which will go to the Genetic Disease Testing Fund, a fund which is continuously appropriated to the department for the purposes of the metabolic disorders testing program.

The test shall not be given to a child whose parent or guardian objects on religious grounds.

Administrative Regulations

Title 17, Subchapter 9 of the California Administrative Code dictates procedures for the timing, testing, and recording procedures to be employed in screening for heritable diseases. Emergency regulations effective October 31, 1980 add hypothyroidism and galactosemia to the newborn screening requirements.

The regulations in the Administrative Code authorize the use of the Guthrie Inhibition Assay and the McCaman-Robins Fluorometric Procedure in screening for PKU. Medical staffs and physicians of hospitals in the state shall see that a blood sample for the PKU test is taken from each infant, as close to discharge of the newborn as possible, but before 20 days from birth. A physician attending an infant not born in a hospital shall have a blood specimen taken between the 4th and 10th day of the infant's life. Specimens shall be sent to an approved laboratory within 24 hours after they are obtained. When an infant is released from the hospital before a specimen for PKU testing is obtained, or when the specimen proves inadequate, the physician shall attempt to obtain a specimen. If he is unable to do so, he shall contact the local health officer within 7 days.

In the event of a presumptive positive initial test, the physician shall arrange for a retest within 7 days of notification of the positive result. If the retest is not feasible, he shall notify the local health officer within 7 days.

When an infant is discharged from a hospital without having been tested for PKU, the hospital shall send written notification to the infant's physician, the local health department of the area where the infant resides, and the State Department of Health, stating the reason the test was not completed.

The regulations also specify the reports to be made to the department by hospitals and local health officers on a periodic basis.

Other Relevant Laws or Regulations

The Hereditary Disorders Act is a comprehensive piece of legislation establishing the purpose and guidelines for screening, counseling, and treatment programs for genetic disorders. The act declares that each person in the state is entitled to health care fitting his or her needs and to protection from improper and inadequate health services. The state policy has been designed to promote programs to alleviate the effects of hereditary disorders through prevention, early detection, and medical treatment.

The act directs the state director of public health to enact rules and regulations establishing the standards to be employed in the hereditary disorders programs of the state.

The act establishes the right of all participants in such state programs to be informed of the risks and benefits of testing, to learn the results of their tests, and to receive informative, nondirective counseling on hereditary disorders. The act also states that test results shall be held confidential and that participation in all programs except

newborn screening for PKU and other diseases added to the newborn screening program shall be entirely voluntary. Participants in all programs except the newborn screening shall be tested only after giving informed consent.

The following programs shall comply with the provisions set forth in this chapter:

- (a) Crippled children's services — Division 1, Part 1, Chapter 2, Article 2.
- (b) Prenatal testing programs — Division 1, Part 1, Chapter 2, Article 2.8.
- (c) Medical testing programs for newborns — Division 1, Part 1, Chapter 2, Article 3.
- (d) Programs of the genetic disease unit — Division 1, Part 1, Chapter 2, Article 3, Section 309.
- (e) Child Health Disability prevention programs under Division 1, Part 1, Chapter 2, Article 3.4.
- (f) Genetically handicapped person's programs under Division 1, Part 1, Chapter 2, Article 3.6.
- (g) Medi-Cal Benefits Programs under Division 9, Part 3, Chapter 7, Article 4.2 of the Welfare and Institutions Code.

Sections 290 to 293 of Article 2.8 require that the State Department of Health Services designate and fund a 3-year pilot program in at least two medical centers to permit the availability of amniocentesis for genetic disorders in certain high risk pregnancies.

Sections 325 to 327 of Article 3.5 assign the State Department of Health the responsibility of designating tests and regulations, which have been enacted, to make every effort to detect, as early as possible, sickle cell anemia. Testing for sickle cell anemia is voluntary and may be administered at the following times: (a) upon first enrollment of a child in elementary school in California; (b) upon first enrollment at junior high or high school in this state, if a child was not tested previously; (c) upon application of any person for a marriage license, the parties seeking the license may be tested; (d) at any other times that the department may so name.

The department may require that a test for sickle cell be given to any identifiable population at high risk.

Chapter 978 (Statute 1977) authorizes the Department of Education to prepare and distribute to school districts guidelines and plans for the implementation of programs for the prevention of genetic diseases, disorders, and birth defects. The county offices of education shall assist school districts in designing plans to provide future parents with practical information concerning, but not limited to, human development, genetics, maternal and child health, nutrition, and environmental effects on fetal and childhood development.

Sections 340 to 348 of Article 3.6 empower the director of health to establish and administer a program for the medical care of persons with genetically transmitted handicapping conditions, including cystic fibrosis, hemophilia, sickle cell disease, Huntington's disease, Friedreich's ataxia, and Joseph's disease. The program developed under this article shall provide any or all of the following: (a) initial intake and diagnostic evaluation; (b) the cost of blood transfusions and blood derivatives; (c) rehabilitative costs, including reconstructive surgery; (d) expert diagnosis; (e) medical treatment; (f) surgical treatment; (g) hospital care; (h) physical therapy; (i) occupational therapy; (j) special treatment; (k) materials; (l) appliances and their maintenance; (m) maintenance, transportation, and other care incidental to the above services; and (n) qualified staff to implement the provisions of this Article.

Section 34 authorizes the director of health to appoint a nine-member advisory committee on this program composed of professional and consumer representatives.

This article also delineates the methods of financial reimbursement and criteria for eligibility for assistance under this program.

Sections 374, 375 and 1374.7 of Article 5 dictate that the State Department of Health shall maintain a central laboratory and branch laboratories to perform the analyses required to meet the responsibilities of the department. This article also outlines standards to be employed with regard to the state laboratory.

Section 10123.3 of the Insurance Code states that (1) no self-insured employee welfare benefit plan shall refuse to enroll any person after appropriate application solely because that person carries a genetic trait that may, under some circumstances, be associated with disability in that person's offspring. Such traits may include, but not be limited to, sickle cell, Tay-Sachs, thalassemia, and X-linked hemophilia A. No insurance plan may require a higher rate or premium because a person carries such traits, nor shall any plan make or require any rebate, discrimination, or discount upon the amount to be paid or the service to be rendered under the plan because an individual carries such traits.

In addition, no discrimination shall be made in the commissions or fees of a solicitor or solicitor firm for a subscription or for the renewal of an enrollment or subscription of any person solely because that person is possessed with a genetic trait such as, but not limited to, Tay-Sachs disease, sickle cell trait, thalassemia trait, and X-linked hemophilia A.

Section 10143 dictates that no insurance company in California shall refuse to issue, sell, or renew any life or disability insurance policy solely because the person is a carrier of a gene that, under some circumstances, may be associated with disability in that person's offspring, but that causes no adverse effects in the carrier. Such traits include, but are not limited to, the above mentioned traits. Subject to the supervision of the Insurance Commission, no policy shall demand or require a higher premium for this reason nor require any rebate, discrimination, or discount upon the amount to be paid or the service to be rendered on such policy. No insurance company licensed in California shall insert in a life or disability insurance contract any condition whereby an insured carrier for a genetic disease with no adverse effect to carrier shall bind himself, his heirs, executors, or assignees to accept any sum or service less than the full amount of the policy.

No insurance company licensed in California shall set any lower rate in the fees or commissions of agents or brokers for writing or renewing a policy of life or disability insurance solely because the applicant is a carrier for a genetic disease that causes no adverse effect to this carrier.

Section 1367.7 of the Health and Safety Code dictates that every health care service plan contract that covers hospital, medical, or surgical expenses on a group basis and that offers maternity coverage in such groups shall also cover expenses of prenatal diagnosis procedures in high-risk pregnancies. Every health care service plan must communicate to all contract holders and groups with whom they are negotiating that this coverage exists.

Section 10123.9 of the Insurance Code states that every group policy of disability insurance that covers hospital, medical, or surgical expenses on a group basis and that offers maternity coverage shall also give coverage for prenatal diagnosis of genetic disorders in cases of high-risk pregnancy.

Section 11512.16 of the Insurance Code mandates that every nonprofit hospital service plan that covers hospital, medical, surgical, and maternity expenses on a group basis must cover prenatal diagnosis of genetic disorders of the fetus in high-risk pregnancies. The availability of this form of coverage must be communicated to group policy and potential policy holders.

COLORADO

Colorado Revised Statutes Sections 25-4-801 to 25-4-804 concern the detection and management of phenylketonuria (PKU) and other metabolic disorders. Under the authority contained in the statute, regulations were adopted to implement the screening program. At this time, Colorado is screening newborn infants for PKU, hypothyroidism, homocystinuria, maple syrup urine disease, and sickle cell anemia.

Newborn Screening Statutes

Sections 25-4-801 to 25-4-804 decree that every newborn infant should be tested for PKU and other metabolic disorders to prevent mental retardation in those children affected. The responsibility for testing each newborn infant rests with the chief medical staff officer or other person in control of each institution for newborns, or, if the child is born outside an institution or discharged before the appropriate time of screening, the responsibility of issuing the test rests with the person signing the birth certificate.

The State Board of Health has the duty to decide the effective tests to be employed for PKU and other metabolic disorders likely to cause mental retardation. In addition, the board has the authority to promulgate regulations concerning the handling, delivery, and testing of specimens. Both the performance of the tests and the reporting of results are to be made at such times, places, and in such manner as may be prescribed by the State Department of Public Health. The department also has the responsibility to contact all cases suspected of having metabolic disorders and to perform any necessary follow-up tests. Testing is not required for the child whose parent or guardian objects due to religious convictions.

Administrative Regulations

"The Detection and Control of Phenylketonuria and other Metabolic Defects" (5 CCR 1005-4) provides for the establishment of procedures for testing, reporting and follow-up of positive cases for metabolic disorders.

CONNECTICUT

Currently, the State of Connecticut has one law pertaining to the testing of infants for the detection of metabolic disorders. This statute authorizes the commissioner of health services to adopt regulations, which have since been promulgated, specifying the diseases to be screened and the methods to be employed. Presently Connecticut is mandated to screen for phenylketonuria (PKU), congenital hypothyroidism, and galactosemia. In recent years, special amendments have been passed concerning specific genetic diseases, including Tay-Sachs, Cooley's anemia, sickle cell anemia, cystic fibrosis, and diabetes. This legislation has resulted in the current availability of laboratory resources for carrier testing or the incorporation of services for a particular genetic disease into the health department program.

Newborn Screening Statutes

Section 19-21b of the Connecticut General Statutes dictates that the administrative officer or other person in charge of each institution caring for newborns shall ensure that every infant in his or her care be tested for PKU, hypothyroidism, galactosemia, and any other disease that may be specified by the Department of Health Services.

The provisions of this law do not apply to any newborn child whose parents find such testing contrary to their religious tenets and practices.

Administrative Regulations

Section 19-13-D41 of the Public Health Code names the administrator of any institution providing medical care to newborn children responsible for the performance of PKU and other prescribed tests. Specimens taken must be submitted within 48 hours after collection to the State Department of Health or to an approved laboratory. Results of the tests must be given to the State Department of Health within 24 hours after the tests have been assayed. Institutions providing medical care to newborns shall maintain records of tests and results for five years.

Section 19-13-D42 of the Public Health Code states that if parents object on religious grounds to the testing of their children in writing, these statements must be reported to the State Department of Health Services and be made part of the infant's hospital record.

A major goal of the code is to assist the Director of Connecticut's Institute of Metabolic Disorders. The code authorizes the board of directors of the institute, which is composed of the mayor, four of the members of the legislative council, and the representatives of the general public, but shall be paid no salary and no expenses. The director of the Department of Health Services shall act as a consultant, non-voting member of the committee.

The major duties of the committee shall be to: (1) design and distribute information on metabolic disorders and the screening program to the public; (2) consult the public, in particular those groups of persons affected by the metabolic disorders program; (3) evaluate continuously the need for and efficiency of screening for PKU and hypothyroidism in the District of Columbia; (4) suggest any additional screening tests for metabolic disorders that may be warranted or other tests which should be deleted; (5) estimate the incidence of such disorders and the cost of the screening and the screening program; and where appropriate send the advice of District and national experts concerning the ethical, medical, psychological, social, and economic effects of such programs; (6) recommend to the mayor the territory which should perform the tests; and (7) report to the mayor and the Council of the District of Columbia a yearly report summarizing the activities of the committee and its recommendations.

The cost of the testing shall be shared by the District of Columbia government. No hospital day charge for the screening program.

Administrative Regulations

There have not been promulgated at the time of this publication.

DELAWARE

The State of Delaware does not have any statutes or regulations specifically concerning the detection, treatment, and care of genetic diseases. However, as of August 1962, the screening of newborns for metabolic disorders was initiated with the PKU Screening Program. Approximately 97 percent of all newborns in Delaware have been screened for phenylketonuria under this voluntary program.

Since 1962, the newborn screening program, now called the Hereditary Metabolic Screening Program, has been expanded to include other metabolic disorders. In January, 1979, these were expanded to provide testing for the following five additional hereditary metabolic disorders: maple syrup urine disease, methionine (homocystinuria), thyroxine (T4), thyroid stimulatory hormone (TSH), and galactosemia.

The objective of the entire testing program is to screen all newborns in order to detect hereditary disorders that, left untreated, could lead to mental retardation or death. All newborns delivered or residing in the State of Delaware are eligible for this service.

DISTRICT OF COLUMBIA

The District of Columbia recently enacted a statute, effective October 1, 1980, requiring certain screening tests for metabolic disorders to be administered to all infants born in hospitals in the District.

Newborn Screening Statutes

Sections 6-211 to 6-219 of the District of Columbia Code mandate testing and follow-up for phenylketonuria (PKU), hypothyroidism, and other metabolic disorders as may be specified in the regulations not yet promulgated.

All hospitals in the District of Columbia shall implement the test procedure. Each test performed must be forwarded to a single laboratory, chosen by the mayor, for assay. The results of these tests must be returned to the hospital where the child was born. Positive test results must be made known to the parent and to a physician named by the District of Columbia government. This physician shall aid the parent and their physician in obtaining adequate follow-up testing and treatment if necessary.

The mayor is prescribed by this statute to assure that carriers of metabolic disorders are not stigmatized or discriminated against by anyone in the District. Policy in the District on metabolic disorders should be made with the advice of experts, and should be reviewed periodically in light of advancing medical knowledge.

Participation in this program to detect metabolic disorders should be wholly voluntary. No woman may be restricted from childbearing, or have the restriction be a condition of eligibility for, or receipt of, any other service or aid from or participation in any other program. Each participant must be informed of any inherent risks involved in the tests, the nature and cost of available treatments for children affected with a disorder, and the risks and benefits of these therapies.

The information obtained from persons involved in the program should be strictly confidential except for statistical data compiled without reference to the individual's identity. The information and the results from the tests will become part of the child's private medical record except for the information released with consent of the parent, who must be made aware of the scope of the information requested for release and the purpose for its release.

Section 6-215 of this code establishes the District of Columbia Committee on Metabolic Disorders. This committee shall be made up of nine members each appointed by the mayor. Four of the members shall be representatives of the general public, four shall be physicians, and one a geneticist or endocrinologist. The directors of the Department of Human Resources shall serve as non-official, non-voting members of the committee.

The responsibilities of the committee shall be to: (1) collate and distribute information on metabolic disorders and the screening program to the public; (2) consult the public, in particular those groups of persons affected by the metabolic disorders programs; (3) reevaluate continuously the need for and efficiency of screening for PKU and hypothyroidism in the District of Columbia; (4) suggest any additional screening tests for metabolic disorders that may be warranted or those tests which should be deleted; (5) consider the incidence of each disorder and the cost of its management and the screening process, and where appropriate enlist the advice of District and national experts concerning the ethical, medical, psychological, social, and economic effects of such programs; (6) recommend to the mayor the laboratory which should perform the tests; and (7) submit to the mayor and the Council of the District of Columbia a yearly report summarizing the activities of the committee and its recommendations.

The cost of the testing shall be absorbed by the District of Columbia government. No hospital may charge for the screening program.

Administrative Regulations

These have not been promulgated at the time of this publication.

FLORIDA

The State of Florida has broadly designed its laws to cover the screening of infants for all metabolic, congenital, and hereditary disorders. Florida has enacted statutes and regulations to achieve that purpose. Presently Florida is screening newborns for the detection of phenylketonuria (PKU), hypothyroidism, galactosemia and maple syrup urine disease.

Newborn Screening Statutes

Section 383.14 of the Florida Statutes names the Department of Health and Rehabilitative Services responsible for promoting the screening of all infants born in Florida for the presence of PKU and other metabolic, hereditary, and congenital disorders known to cause significant impairment of intellect and health. As screening programs accepted by current medical practice become more available and practical in the judgement of the department, they shall be initiated. The methods and timing of the performance of such tests shall be prescribed by the department after consultation with the Infant Screening Advisory Council.

The department shall, after consultation with the council, implement and enforce rules requiring that every infant born in Florida be tested for PKU and at the proper age, for such other metabolic diseases and hereditary or congenital disorders as the department dictates. Additional rules may be promulgated, as they are deemed necessary by the department after consultation with the council, to appropriately administer this statute. These may include rules relating to the manner and timing to be employed in the testing procedures and the requirement of mandatory reporting of the test results to the department.

The department shall administer and provide certain services to put into effect the provisions of this section and shall: (1) insure that the necessary laboratory tests and materials be available and of high quality; (2) furnish the forms to be used to record test results; (3) promote educational programs to enlighten the public on the prevention and management of metabolic, hereditary and congenital disorders; (4) maintain a confidential case registry; (5) supply needed dietary treatment products not otherwise available; and (6) encourage the availability of genetic studies and counseling.

The provisions of this statute will not apply when the parent or guardian of the child objects to the testing. A written statement of this objection must be given to the physician or other person responsible for administering and reporting the tests.

This statute also mandates the establishment of an Infant Screening Advisory Council comprised of 10 members appointed by the secretary of the department. This council is composed of two consumer members, two practicing pediatricians, one representative of each of three medical schools in the state, and one representative each from the Children's Medical Service Program Office, the Health Program Office, and the Retardation Program Office.

Administrative Regulations

Florida Administrative Code 10D-76.01 to 10D-76.07 outlines the duties of the responsible parties, the criteria for approval of laboratories, and the methods, timing, and recording procedures employed in the implementation of Section 383.14 of the Florida Statutes.

According to these rules, every live newborn infant in Florida must have a blood test for the detection of PKU, hypothyroidism, galactosemia, and maple syrup urine disease unless the parent or guardian of the child objects. Hospitals in the state shall make the necessary arrangements for the tests to be performed as a unit by an approved laboratory. When a birth occurs in a hospital, the responsible physician shall assure that the test specimen is obtained prior to the infant's discharge from the hospital. Should the infant need to be tested again for these diseases, the hospital administration or designated representative of the institution shall furnish a written notice to the parent or legally responsible person, at or before discharge, requiring the child to be retested.

When a child is not born in a licensed hospital, it shall be the duty of the person in attendance at the birth to ensure that the newborn is referred to a facility where the tests may be performed.

The laboratory assaying the test specimens shall send a written report of the results to the hospital or other facility where the birth occurred or to the responsible physician within 7 to 10 days after receipt of a specimen. This report shall become part of the patient's record.

In the event of an abnormal test result, the laboratory shall immediately telephone this result to the department and follow with a written report. The department, in turn, must notify by telephone the responsible physician and the designated Regional Genetics Center. If there is no known responsible physician, this notification shall go to the county health unit in the county of the mother's residence. After receiving this information, the hospital, responsible physician, or county health unit is requested to immediately notify the parent or guardian and recommend further diagnostic and therapeutic procedures.

The department shall also be responsible for the screening of all newborns and for the screening of the screening program. The department shall also be responsible for the screening of all newborns and for the screening of the screening program. The department shall also be responsible for the screening of all newborns and for the screening of the screening program.

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Administrative Regulations

Chapter 290-2-24 Testing for Inherited Disorders in the Newborn of the State of Illinois. Resources were recently adopted, pursuant to the above statute.

These rules state that every newborn infant shall have a blood test after the patient has given written consent. Unless the parent objects to newborn screening. When a child is born in a hospital, the physician shall have a blood specimen taken prior to the infant's discharge. If the infant is discharged from a hospital before the blood specimen is taken, the parent must be tested again before 1 week of age, although a second test is not needed for a newborn who has a blood specimen taken at the designated representative of the hospital after 1 week of age. Notice of these requirements to the parent, guardian or other legally responsible person.

When a live birth occurs in a facility other than a hospital, it shall be the responsibility of the parent or other of the facility or the person in attendance to give written notice to the parent's guardian of the legal requirements for the newborn to be tested and to advise where such testing can be obtained.

The blood sample and required patient information must be sent to an approved laboratory on the day of collection. Laboratories performing the test for the detection of PKU, galactosemia, phenylketonuria, homocystinuria, maple syrup urine disease, tyrosinemia, and sickle cell hemoglobin shall report their results to the attending physician and the hospital where the birth occurred and the results shall become part of the child's clinical medical record. In addition, test results for sickle cell hemoglobin must be sent by the laboratory to the county health department of the child's residence. All results of tests for other disorders shall be sent by the laboratory to the central laboratory of the department on the day the testing is completed. In the event of an abnormal test result for PKU, maple syrup urine disease, galactosemia, homocystinuria, or tyrosinemia, the laboratory shall notify within 10 hours the appropriate medical facility where a nurse will telephone the attending physician. If the physician cannot be reached, the medical facility must then contact the parent. If they cannot be located, or are nonresponsive, the medical facility will contact the local health department for assistance. If the blood test indicates either sickle cell anemia or sickle cell trait, the attending physician and/or county health department must inform the parent or legal guardian of this diagnosis and the consequences on the disease and available treatment.

GEORGIA

Georgia has promulgated one law concerning the testing of infants for inherited metabolic diseases, sickle cell anemia and the sickle cell trait. This law authorizes the establishment of rules and regulations, which have been promulgated for the implementation of this statute. In addition, Georgia has passed an insurance code relating to insurance coverage of newborns for medically diagnosed congenital defects and abnormalities.

Newborn Screening Statutes

Code of Georgia Chapter 88-12 authorizes the Department of Human Resources to promulgate rules and regulations governing tests for phenylketonuria (PKU), sickle cell trait, galactosemia, tyrosinemia, homocystinuria, maple syrup urine disease, hypothyroidism and other inherited disorders.

The entire process for screening and following up possible cases of the metabolic disorders must occur within the first three weeks of an infant's life.

In the event that any child is found to have PKU, sickle cell anemia or sickle cell trait, the examining physician or public health department shall be responsible for notifying the parents of this finding. The parents shall also be informed that if such child has sickle cell anemia or the sickle cell trait, counseling concerning the nature of the disease and its treatment is available at no cost from the Department of Human Resources, the county board of health or the county department of health. It shall be the duty of the Department of Human Resources and each county board of health and county department of health to furnish, without cost, counseling to any person who requests information about sickle cell anemia or the sickle cell trait.

The department shall be responsible for the screening of all newborns and for the assessment of the screening program. This department shall also, to the extent state and Federal funds are available, provide for retrieving potentially affected screenees back into the health care system; accomplishing specific diagnoses; initiating and continuing therapy; and assessing the program. The department shall utilize existing appropriate resources whenever possible and work with other agencies and organizations to create an effective system.

The department and appropriate medical centers shall work together in the development and implementation of a statewide network for medical genetics. This network will have the duty of training personnel in genetics, research and development concerning metabolic disorders, and quality control of laboratory services for genetics. This network shall also provide counseling for genetic disorders.

Administrative Regulations

Chapter 290-5-24, Testing for Inherited Disorders in the Newborn, of the Rules of the Department of Human Resources was recently adopted, pursuant to the above statute.

These rules state that every newborn infant shall have a blood test after the parents have given written consent, unless the parents object on religious grounds. When a child is born in a hospital, the physician shall have a blood specimen taken prior to the infant's discharge. If the infant is discharged from a hospital before 48 hours after birth, the newborn must be tested again before 1 week of age, although a second test is not needed for a sickle cell hemoglobin detection. The administrator or the designated representative of the hospital must provide written notice of these requirements to the parents, guardian or other legally responsible person.

When a live birth occurs in a facility other than a licensed hospital, it shall be the responsibility of the person in charge of the facility or the person in attendance to give written notice to the parents or guardian of the legal requirements for the newborn to be tested and to advise where such testing can be obtained.

The blood sample and required patient information must be sent to an approved laboratory on the day of collection. Laboratories performing the tests for the detection of PKU, galactosemia, tyrosinemia, homocystinuria, maple syrup urine disease, hypothyroidism, and sickle cell hemoglobin shall report all test results to the attending physician and the hospital where the birth occurred and the results shall become part of the child's clinical medical record. In addition, test results for sickle cell hemoglobin must be sent by the laboratory to the county health department of the infant's residence. All results of tests for other disorders shall be sent by the laboratory to the central laboratory of the department on the day the testing is completed. In the event of an abnormal test result for PKU, maple syrup urine disease, tyrosinemia, homocystinuria, galactosemia, or hypothyroidism, the laboratory shall notify within 24 hours the appropriate medical facility who, in turn, will telephone the attending physician. If the physician cannot be reached, the medical facility must then contact the parents. If they cannot be located, or are nonresponsive, the medical facility will contact the local health department for assistance. If the blood tests indicate either sickle cell anemia or sickle cell trait, the attending physician and/or county health department must inform the parents or legal guardian of this diagnosis and give counseling on the disease and available treatment.

Other Relevant Laws or Regulations

Code of Georgia Annotated Chapter 56-2441 states that all individual and group health insurance policies providing coverage on an expense incurred basis and individual and group service or indemnity type contracts issued by a nonprofit corporation that provide coverage for a family member of the insured or subscription holder shall also provide that the health insurance benefits applying to children be payable with respect to a newly born child of the insured or subscriber from the moment of birth. This policy shall consist of coverage for injury or sickness including the necessary care and treatment of medically diagnosed congenital defects and birth abnormalities.

HAWAII

The State of Hawaii has established a program for the screening of newborns to detect the presence of phenylketonuria (PKU). Pursuant to enacted statutes, Hawaii has adopted regulations concerning the screening of newborn infants for hereditary disorders.

Newborn Screening Statutes

Hawaii Revised Statutes Section 333-1 states that the physician, midwife, or other person attending the birth of a child shall ensure that a PKU test is administered to the child. This does not apply to a child whose parent, guardian, or other person having custody over the child objects for religious reasons.

Administrative Regulations

Chapter 36 of the Public Health Regulations names the physician, midwife, or other person attending a newborn child responsible for causing the newborn infant to be administered appropriate screening tests, approved by the department, which have been designed to detect specific metabolic disorders. The person attending the child shall have the duty to record such tests. In the event that a written objection has been made, the physician or other responsible person must record the objection and send the name of the child to the Hereditary Metabolic Disease Register.

The laboratory performing the analysis of the tests shall promptly report any positive or presumptive positive screening results and the name of the child to the Hereditary Metabolic Disease Register and the person responsible for recording the screening test.

The Hereditary Metabolic Disease Register shall be established in the Department of Health to record and maintain the name of any child who has a positive or presumptive positive test for the conditions specified, as well as the physician, midwife or other person attending such child, and any confirmed diagnosis. The department must follow up all positive or presumptive positive test results in cooperation with the attending physician. The services and facilities of the department shall be made available to the families of affected children who are not financially able to meet the medical, dietary, and related needs of the children.

Any person violating the provision of this regulation shall be guilty of a misdemeanor punishable by a fine not to exceed \$500 and/or imprisonment for up to 1 year.

Administrative Regulations

Chapter 360-126, Testing for Inborn Errors in the Newborn, of the Rules of the Department of Health, contains the administrative regulations pursuant to the above statute.

These rules state that every newborn infant shall have a blood test after the parents have given written consent, unless the parents object on religious grounds. Where a child is born in a hospital, the hospital shall have a blood specimen taken from the infant's heel. If the infant is discharged from the hospital before 72 hours after birth, the newborn must be tested again before 1 week of age. Should a specimen not be received for a child still in hospital detention, the hospital must, at the request of the designated representative of the hospital, send a written notice of these requirements to the parent, guardian or other legally responsible person.

Where a birth occurs in a laboratory, other clinic, home, and hospital, it shall be the responsibility of the person in charge of the facility to ensure that the newborn is given the blood sample by the parent or guardian of the legal requirements for the newborn to be tested and to advise which person has the responsibility.

The blood sample and required genetic information must be sent to the approved laboratory on the day of collection. Laboratories performing the tests for the detection of PKU, galactosemia, tyrosinemia, homocystinuria, maple syrup urine disease, hypothyroidism, and sickle cell hemoglobin must report their results to the attending physician and the hospital where the birth occurred and the results must be part of the child's clinical medical record. In addition, test results for sickle cell hemoglobin must be sent by the laboratory to the county health department or the infant's residence. All results of tests or other laboratory must be sent by the laboratory to the central laboratory of the State Department of Health on the day the testing is completed. In the event of an abnormal test result for PKU, maple syrup urine disease, homocystinuria, hypothyroidism, galactosemia, or hypothyroidism, the laboratory shall advise within 24 hours the appropriate medical facility which, in turn, will telephone the attending physician. If the physician cannot be reached, the medical facility will then contact the parents. If they also cannot be located, or are unresponsive, the medical facility will contact the local health department for assistance. If the local health department cannot be reached, the attending physician and/or county health department must inform the parents of the abnormal test results and give counseling on the disease and available treatment.

IDAHO

Idaho Code Sections 39-909 through 39-912 are concerned with the testing of infants for phenylketonuria (PKU) and other preventable diseases. Rules and regulations have been promulgated that outline in detail procedures and responsibilities for the testing. Idaho has also established an insurance law that stipulates that a contract providing coverage for injury or sickness for dependent children of subscribers or other persons covered by the insurance must provide that coverage for such newborns suffering from congenital anomalies. In addition to testing infants for PKU, presently Idaho tests for hypothyroidism, galactosemia, maple syrup urine disease, homocystinuria, and tyrosinemia.

Newborn Screening Statutes

Under Idaho Code Sections 39-909 through 39-912, all infants in Idaho are to be tested for the detection of PKU and other preventable diseases as prescribed by the State Board of Health and Welfare. The director of the Department of Health and Welfare is empowered to: (1) enforce the stipulations of the statute; (2) dictate what tests are to be employed for the detection of other preventable diseases and PKU; (3) publish rules and regulations of the Board of Health and Welfare on the method and timing of the tests; (4) provide copies of the act and regulations to physicians, hospitals, and other persons or institutions required by this law to administer the tests; (5) establish and maintain a record of all positive cases for any of the diseases being tested for and supervise local health agencies in the treatment and amelioration of the diseases; and (6) distribute information and recommendations to the public on the nature, detection, and treatment of PKU and other such preventable diseases.

A violation of this statute constitutes a misdemeanor punishable by law.

A child may be excused from the mandated testing should his or her parent or guardian object because such testing is contrary to the beliefs of a recognized church or religious denomination to which the parent or guardian belongs.

Administrative Regulations

Regulations 5-2001 through 5-2006, authorized by Section 39-904, describe specifically the test procedures to be used in the screening of newborns for PKU and other preventable diseases that may result in various developmental disabilities and that are amenable to early detection by available screening procedures.

The regulations also describe the duties of the responsible individuals and laboratories. In essence, the responsibility for the testing procedure rests upon the administrator of the institution where the child was born and upon the person required to register the child's birth. The administrator must make certain that the tests are administered and that specimens are forwarded, along with the name of the hospital and the attending physician, date of birth, and date the specimen was taken, to the laboratory named by the Department of Health and Welfare. This administrator must also maintain a record of all specimens collected, indicating the above information and the name of the person collecting the specimen. Whenever possible, the administrator shall make the hospital laboratory responsible for the collection of the test specimens. The hospital may charge for this service. The person who is responsible for the birth registration of the child must record on the birth certificate whether the PKU test has been performed.

Other Relevant Laws or Regulations

Idaho Code Sections 41-2210 and 41-3437 of the State Insurance Laws establish that any insurance contract, whether a group disability, blanket disability, or individual type, which covers injury or sickness for dependent children of anyone covered by the policy, must provide coverage for newborns from and after the moment of birth. This coverage shall include, but not be limited to, coverage for congenital anomalies.

ILLINOIS

In 1965, Illinois enacted a statute mandating the screening of infants for phenylketonuria (PKU) and other metabolic diseases that the Department of Public Health deems necessary. This statute empowers the department to adopt rules and regulations, which have since been promulgated and amended, as necessary for the administration of the act. At this time newborns are screened for PKU and hypothyroidism. Illinois has also promulgated an act and regulations establishing a program for the care of persons with hemophilia.

Newborn Screening Statutes

Chapter 111½, Sections 4903 to 4905 of the Illinois Revised Statutes authorize the Department of Public Health to enforce regulations requiring that every newborn be administered a test for PKU and other metabolic diseases as may be specified.

The department shall also perform the following functions: (1) maintain a registry of cases, including information for the purpose of follow-up services to prevent the onset of mental retardation; (2) furnish the necessary treatments where practicable for diagnosed cases when these treatments are not available through other state agencies; (3) arrange for and supply public health nursing, nutritional and social services, and clinical consultation when necessary; and (4) initiate and maintain an educational program on the nature of PKU and other metabolic disorders and the tests for their detection for physicians, hospital personnel, public health nurses, and the public.

The provisions for infant screening may be waived if the parent or guardian of the child finds that the test conflicts with his or her religious beliefs and customs. A written statement of this objection must be given to the physician or other person responsible for the testing.

Administrative Regulations

The regulations for the statute name the attending physician responsible for assuring that the infant is given a blood test for PKU and hypothyroidism. The physician may delegate this duty to the hospital administrator or the administrator's designated representative if the infant remains in the hospital for at least 24 hours after the first protein feeding. If there is no physician in attendance, the physician caring for the infant during his first month of life shall be responsible for the performance of the tests. The parent or guardian assumes this responsibility when there is no physician caring for the infant. Local or state health authorities shall assist the parents in this endeavor.

The regulations also describe the specific tests to be employed and the methods for the collection and interpretation of the specimens.

Finally, the Department of Public Health, in collaboration with the Division of Services for Crippled Children, shall keep a file of designated pediatric consultants and endocrinologists and shall make this known to the attending physicians of patients with test results other than negative. The department shall also maintain a registry of the results of the diagnosis and treatment of all cases in which abnormal measurements were found.

If the test is not performed on an infant because a parent or guardian delivers a written statement of objection on religious grounds, a report must be sent to the Division of Family Health on the day the infant is discharged from the hospital.

Other Relevant Laws or Regulations

The Hemophilia Program Act, Chapter 111½, Section 2901, adopted in 1977, provides that a program for the care of hemophiliacs be created within the Department of Public Health. The department shall establish this program for the care and treatment of hemophiliacs who are unable to pay for the whole cost of such services on a continuing basis despite the existence of various types of medical and hospital insurance, government medical or financial aid programs, and private charities. With the advice of the Hemophilia Advisory Committee, the department shall develop criteria for determining eligibility for the support services available under this program.

The Department of Public Health shall also: (1) assist in the development and enlargement of care and treatment plans for hemophiliacs, including self-administration and other medical and dental procedures; (2) extend financial support to persons deemed eligible for blood, and blood derivatives and concentrates; (3) institute and maintain educational programs for physicians, hospitals, public health departments, and the public on hemophilia; (4) distribute information on the disease, its treatment and prevention; and (5) enact rules and regulations for the implementation of the provisions set forth in this statute.

This statute also creates the Hemophilia Advisory Committee, which will consult with the department on the administration of the act. This committee shall include 15 members representing hospitals, volunteer agencies, blood bank associations, local public health agencies, medical specialists, and the public.

The regulations authorized by the Hemophilia Program Act outline the standards to be employed in determining eligibility for the services supplied through the act. The regulations also describe the criteria that must be met by the hemophilia centers and the responsibilities of the primary care physician and dentist testing hemophiliacs. Hemophilia patients registered in the program must be given a complete examination at least once a year in an approved hemophilia center, and a written statement that the examination has been performed must be sent to the program coordinator each year by the center director.

INDIANA

The State of Indiana has enacted a number of laws concerning the prevention, detection, and treatment of genetic diseases. Sections 16-8-6-1 to 16-8-6-6 of the Indiana Code concern the screening of infants for phenylketonuria (PKU), hypothyroidism, and other metabolic diseases that may result in mental retardation if left untreated. Indiana has also enacted statutes and regulations relating to the testing of persons for sickle cell anemia. Finally, the state has passed a law establishing the Hemophilia Care Program.

Newborn Screening Statutes

Sections 16-8-6-1 through 16-8-6-6 of the Indiana Code state that every infant shall be given a test at the earliest feasible time for the detection of PKU, hypothyroidism, and other metabolic disorders.

The State Board of Health shall, with the advice of medical authorities, determine and request proper tests to be employed in the detection of PKU. The state board and all local boards of health shall encourage and promote the implementation of programs for the detection of this disorder.

Each hospital and physician is responsible for ensuring that a blood specimen from every newborn infant is collected and sent to a laboratory to be analyzed for hypothyroidism and other inborn errors of metabolism as may be required by the State Board of Health.

The board shall name one or more laboratories for the testing for hypothyroidism and other metabolic disorders. These laboratories, as well as any hospital, shall perform tests on all infants for the detection of PKU. The board shall require that physicians and hospitals report the results of those tests performed to detect PKU.

An advisory committee, established by this statute, assists the board and laboratories it designates for testing for inborn errors of metabolism.

Administrative Regulations

At this time, the state has promulgated no formal regulations governing newborn screening programs.

Other Relevant Laws and Regulations

Indiana Code Section 20-8.1-7-10, amended by Public Law 150, Acts of 1980, requires the immunization of all children enrolled in schools. The statute dictates that whenever a child enrolls in a school corporation, the governing body of that school shall require the parents to supply a written statement of the child's immunization, along with a physician's certificates or other documents and testing history, unless the written statement and documents are on file at the school. The statement shall include, but not to be limited to, information on whether or not the child has been tested for sickle cell anemia. This statement shall also indicate the results of any test for the detection of sickle cell anemia. No child will be permitted to attend school for more than 30 days beyond the date of enrollment without furnishing this written statement. All parents must adhere to this reporting requirement and an objection on religious grounds will not exempt them from this section.

Section 20-8.1-7-14 states that a sickle cell anemia test should be administered to every pupil when the school nurse or examining physician determines it necessary. The physician shall indicate on the examination form whether the test was given, and, if so, the result. All positive results must be filed with the examining physician and the State Board of Health.

The Board of Health and Board of Education shall enact rules and regulations relative to sickle cell anemia screening equipment, qualifications for testing personnel, and procedures. Records of all tests must be continuously maintained by the Board of Health for the purpose of providing information useful in protecting and promoting the health of Indiana's school children.

Indiana Administrative Code 410.1-1-2 regulates the provisions established in the sickle cell screening statute.

Indiana Code Section 16-1-14.5 empowers the governor to appoint a Hemophilia Advisory Committee to advise the Department of Health in the administration of the following provisions. The Board of Health, after consultation with the committee, shall: (1) develop standards for determining eligibility for care and treatment under this program; (2) assist in the development of programs for the care and treatment of hemophiliacs, including prevention and home care or other medical and dental procedures aimed at providing maximum control over the disease, and self-administration; (3) extend financial aid to hemophiliacs so that they may obtain blood, blood derivatives, and other efficacious substances, or participate in the cost of blood processing to the extent that this support facilitates the greater supply of blood, blood derivatives, and other necessary agents at an economical cost; and (4) promulgate rules and regulations necessary to implement the goals of this statute.

IOWA

At present, the State of Iowa has one statute pertaining to the testing for metabolic disorders, Iowa Code Section 135.31, Test for Phenylketonuria. At this time, newborn infants are screened only for phenylketonuria (PKU). In addition, Iowa has passed Section 136A in 1976, establishing the Birth Defects Institute.

Newborn Screening Statutes

Iowa Code Section 135.31 mandates the screening of all infants born in Iowa for the detection of PKU, insofar as practicable. All state, district, county and city health and welfare agencies must cooperate with the State Department of Health to implement this policy directive. Iowa has proposed a voluntary testing program for the following diseases: hypothyroidism, maple syrup urine disease and galactosemia. This program is to be implemented in the fall of 1980.

Administrative Regulations

Standards to be employed in this program have been established by a subcommittee of medical specialists. These standards will be reviewed in July 1980 by the Iowa Board of Health, and, if approved, will have the force of law though they will remain uncoded.

Other Relevant Laws or Regulations

The Birth Defects Institute, created under Iowa Code Section 136A, was established for the purposes of studying the etiology and mortality rate, and determining methodologies for treatment, prevention, and cure of birth defects and related diseases. The Birth Defects Institute is empowered to conduct scientific inquiries and to publish and disseminate the findings of this research to the scientific community. The Institute may initiate professional education programs for medical students, physicians, nurses, scientists, and technicians concerning the causes, treatment, prevention, and cure of birth defects. Lastly, the Institute may operate and support programs for clinical counseling in medical facilities.

KANSAS

Kansas statutes first established in 1965 and amended in 1977 provide for the testing of newborn infants for congenital hypothyroidism and phenylketonuria (PKU). The state also has an amended statute on screening for sickle cell anemia.

Newborn Screening Statutes

Kansas Statutes Annotated Section 65-180 empowers the Kansas Secretary of Health and Environment to: (1) initiate and implement an educational program for physicians, hospitals, public health nurses, and the public on congenital hypothyroidism and PKU to explain the disorders and the tests for their detection; (2) make provisions for recognized screening, diagnostic and treatment control tests for PKU, hypothyroidism, and other disorders that may be diagnosed with the same procedure (these tests are to be made by the Office of Laboratory Services at no charge); (3) establish a registry of cases to insure follow-up services to prevent mental retardation; and (4) supply treatment for diagnosed cases, as long as medically necessary, when such a service is not provided through other state agencies. Section 65-181 places the responsibility of giving the tests on the administrative officer or other person in charge of each institution or the attending physician. The secretary of the Department of Health and Environment shall prescribe the method and timing for the testing and the recording of results.

Section 65-182 indicates that the above procedures are to be waived when the parents object for religious reasons. The final section on testing for congenital hypothyroidism and PKU, Section 65-183, dictates that any physician who knows of a positive case of one of these diseases must report it to the secretary of the Department of Health and Environment.

Administrative Regulations

At the present time, Kansas has not promulgated formal regulations.

Other Relevant Laws or Regulations

Kansas Statutes Annotated 1977 Supplement 65-1,105 was amended in 1978 to authorize the secretary of the Department of Health and Environment to establish a statewide program of sickle cell testing. The program is intended to test for the sickle cell trait and for sickle cell anemia, and to furnish, at no cost, counseling about the disease and the trait to any person who requests it. Although the statute does not mention the need for the consent of each individual or his or her parent, the test is meant to be a voluntary procedure on the part of the testee. The secretary is empowered to contract with any city, county, or joint board of health, or with any private health organization, to aid in the provision of the testing and counseling.

A program of financial assistance for persons affected by the disease who can not pay for their care and treatment is also established by this statute. It was the intention of the legislature that any state resident with sickle cell anemia should not have to expend so much of his or her income or assets as to bring 'unjust and unusual hardships to such person and to the person's immediate family'.

If a third party has a legal obligation to pay the cost or any part of the cost of such treatment to or on behalf of the recipient, the secretary may recover the expenditures made by the department from this third party, or from the recipient.

The secretary is authorized to adopt rules and regulations and establish standards for determining financial eligibility for assistance to achieve the goals of this act.

Indiana Administrative Code 410.1137 regulates the procedures established in the sickle cell screening statute. Indiana Code Section 16-1-14.5 empowers the governor to appoint a Hemophilia Advisory Committee to advise the Department of Health in the administration of the following provisions: The Board of Health, after consultation with the committee shall: (1) develop standards for diagnosing eligibility for care and treatment under this program; (2) assist in the development of programs for the sale and distribution of hemophiliacs, including prevention and home care of viral hepatitis; and mental procedures for the care of hemophiliacs; (3) advise the governor on the development of a fund to provide financial aid to hemophiliacs who may obtain blood, blood derivatives, and other efficacious substances, or participate in the care of blood, providing to the extent that the support facilitates the greater supply of blood, blood derivatives, and other necessary agents at an economical cost; and (4) promulgate rules and regulations necessary to implement the goals of this act.

KENTUCKY

One law has been enacted by the State of Kentucky relating to the testing of newborns for metabolic disorders. Presently phenylketonuria (PKU), hypothyroidism, and galactosemia are screened in newborn infants. In addition, Kentucky has a statute concerning the creation of a hemophilia advisory committee and a hemophilia treatment program.

Newborn Screening Statutes

Kentucky Revised Statutes Sections 214.155 (1) and (2) require infants to be tested for PKU and other inborn errors of metabolism. This section makes the administrative officer in charge of institutions caring for newborns responsible for administering the tests and recording the results. The rules, regulations, and standards for the testing and recording of the results are to be authorized by the secretary of human resources. This testing is to be waived if the parents are members of a nationally recognized and established church or religious denomination, the members of which are opposed to medical tests and object in writing to the testing of the child.

Administrative Regulations

The relevant section of the Kentucky Administrative Regulations, 902 KAR 4:030, was recently amended to include the testing not only for PKU but also for galactosemia and hypothyroidism. The person in charge of the hospital or other institution caring for the infant and the attending physician or midwife has the responsibility to insure that the proper blood tests for these disorders are issued. Should the child be born outside an institution it is the sole responsibility of the physician or midwife to test the infant. The blood samples taken may be submitted to the Department of Human Resources, Bureau for Health Services, Laboratory Services for laboratory analysis at no cost. The institution may also conduct its own testing analysis program. In this case, the department must be notified, the procedure employed must be approved, and a report must be filed within 24 hours to the department and the attending physician in the event of a positive test.

Other Relevant Laws or Regulations

The hemophilia statutes were promulgated in 1976. Section 211.740 provides for the establishment of a hemophilia advisory committee for the purpose of advising the Bureau for Health Services regarding the hemophilia treatment program initiated by Section 211.750. The hemophilia treatment program was established by the Bureau for Health Services to: (1) detect, diagnose, and treat persons with hemophilia and related diseases in programs including, but not confined to, home care; (2) develop and expand existing programs with medical and dental care designed to achieve maximum control over bleeding; (3) educate the community on the detection of hemophilia and counsel affected families and individuals; (4) initiate and monitor educational programs for members of the health community on the methods of detection, diagnosis and treatment; and (5) provide financial aid to those affected who are unable to afford the costs of continuing treatment to avoid crippling, hospitalization, or other damaging effects associated with hemophilia.

LOUISIANA

In the State of Louisiana, programs for preventing, detecting, and treating phenylketonuria (PKU), congenital hypothyroidism, and meniscocytosis (sickle cell anemia) are defined by statutes. Louisiana has also enacted a law establishing a hemophilia advisory committee and a state treatment program for hemophilia.

Newborn Screening Statutes

Louisiana Revised Statutes Section 40:1299 authorizes the Department of Health and Human Resources to establish, implement, and maintain programs designed to ameliorate the effects of meniscocytosis (sickle cell anemia), PKU, and hypothyroidism. Under this law, the department must set up a diagnostic laboratory for conducting experiments and projects to develop procedures for the early detection, prevention, and treatment of the three diseases in children, and for any other program deemed necessary by the department. Rules and regulations essential to application of the program may be adopted by the department.

Section 40:1299.1 describes standards for the timing and recording of the tests. The physician or person attending the newborn is responsible for insuring that the child is tested for PKU, congenital hypothyroidism, and sickle cell anemia. No examination may be given to any child whose parents object. In the case of a positive test, the attending physician or other person must notify the department. The department must follow up all positive tests with the attending physician and with the parents of the newborn and inform the physician and/or parents of the services and facilities that are offered by the department and other state boards, departments, and agencies that aid the Department of Health and Human Resources in this program's implementation.

The next paragraph, 40:1299.2, stipulates that any of the various boards, commissions, departments, and agencies of the state and of the parishes, municipalities, and other political subdivisions that are capable of assisting the Department of Health and Human Resources in the provisions of the above program may cooperate with the department and may furnish any such services and facilities.

Section 40:1299.3 invites the cooperation of physicians and hospitals within the state that provide obstetric and pediatric care to join the established programs of the department.

Administrative Regulations

The department has not promulgated formal regulations.

Other Relevant Laws or Regulations

Section 40:1299.4 provides for the establishment and operation of clinics, in association with the Louisiana State and Tulane University Medical Schools, for the treatment of sickle cell anemia. These clinics, authorized by the Department of Health and Human Resources, shall be located in Charity Hospital of Louisiana at New Orleans and Huey P. Long Charity Hospital, Pineville. The clinics shall treat all persons with sickle cell anemia without regard to the standard eligibility requirements of a charity hospital or the geographic and economic situation of the patient's family. The clinics shall also be the sites for the training of physicians and medical students in the management of sickle cell anemia.

In reference to the testing program for these metabolic, hereditary, and congenital disorders, the law of Louisiana does not allow anyone employed by the state or by any public or private social service agency that is a recipient of government assistance to require or recommend that any woman have an abortion. This law, Section 40:1299.34, does not apply to state-licensed physicians who may be acting to preserve the life of the pregnant woman.

The state of Louisiana has also promulgated a law relating to sickle cell anemia with respect to school-age children. Louisiana Revised Statute 17:170 dictates that all children, upon entering school within Louisiana for the first time, must provide satisfactory evidence of being or having been tested for sickle cell anemia. Without such evidence, the student will be given a test for sickle cell anemia, unless a parent objects or provides for the testing of the child by a private physician or parish health unit where the school is located.

If a child is transferring into a school system from within or without Louisiana, a certificate or statement indicating the performance of a sickle cell anemia test on the child must be submitted.

If the results of this test are positive or inconclusive, the private physician or parish health unit must submit written documentation of this result to the school board of the city or parish where the child lives. Documentation of the result may also be sent to any representative designated by the public school board or appropriate governing body if the school is a licensed day care center or kindergarten.

There have been no regulations mandated by the state of Louisiana to implement these statutes. The state, however, through the Department of Health and Human Services, has formulated policy manuals on PKU and hypothyroidism for the facilities run by the state. A policy manual for sickle cell anemia is in the process of being written. Private facilities and physicians are not bound to follow these policy manuals, though many do.

No child may be required to comply with the provisions of the statute if the parent or guardian presents a written objection to the test.

Louisiana Revised Statute 40:1299.5, enacted in 1977, provides for the establishment of a program for the care and treatment of hemophiliacs. The program aids persons who cannot afford the costs of such services on a continuing basis, but who have a requisite need for continuing treatment with blood and blood derivatives.

The Department of Health and Human Resources shall institute standards for determining eligibility for care and treatment under this program. Moreover, the department will financially assist hemophiliacs in obtaining blood and its derivatives and any other necessary products for use in hospitals, dental and medical facilities, and at home. The department may also help fund projects for blood processing that will enable the hemophiliac to purchase necessary products at more economical cost. Finally, the department will institute and support educational programs for health care providers, schools, and the public concerning the nature, care, and treatment of hemophilia.

Section 238 of the Louisiana Code of Health and Mental Hygiene, which is part of the Louisiana Revised Statutes, gives the secretary of health and mental hygiene the responsibility to approve the rules and regulations within the standards set by the commission, to enforce the rules of the commission, and to inform the commission of the progress of the program and of any need for change in the rules.

Administrative Regulations

The Commission on Hereditary Disorders has promulgated regulations governing the administration of newborn screening programs. In the Code of Maryland Regulations 10.28.01, the commission specifies the questions to be asked for, the person responsible for the testing, the laboratory, referral and reporting procedures to be followed, the counseling to be offered to parents or guardians, and the records to be kept.

The regulations specify that all newborns in the state shall be tested, unless the parent or guardian objects. The test shall screen for PKU, maple syrup urine disease, and any other hereditary metabolic disorders specified by the Department of Health and Mental Hygiene with the approval of the commission. Presently in addition to PKU and maple syrup urine disease, hypothyroidism, galactosemia, and homocystinuria are being screened in newborn infants.

The person in charge of the institution where the child is born is responsible for seeing that the screening test is administered. If the child is born outside an institution, the responsibility for having the screening test administered rests with the individual required by the characteristics of birth. In either case, the written approval of the parent or guardian must be obtained before the test is administered.

The regulations strongly recommend that a second test be administered before the child is 4 weeks old. Oral or written consent of the parent or guardian should be obtained for the second test.

The regulations specify that the laboratory analyses shall be performed by the department or by a laboratory approved by the department and the commission. All specimens shall be forwarded to the laboratory within 24 hours after collection. The laboratory will report the results to the appropriate institution or physician within 7 days after receiving the specimen.

The director of every laboratory performing analyses of these specimens will notify the department, within 1 week of receiving the specimen, of every abnormal result. The department will follow up every abnormal test result by contacting the appropriate institution or institution, which shall try to obtain a second sample. If the parent or guardian fails to respond to the request for a second test, the department will be informed and will try to notify the parent or guardian of the importance of a follow-up test. If a follow-up test establishes the presence of a metabolic disorder, the department will notify the physician or local health department and will recommend sources of treatment.

The department will provide counseling to the parent or guardian requesting it. The counseling shall be informative and non-directive.

The department will maintain a register of every newborn diagnosed as having a hereditary disorder. The records shall be held confidentially.

MAINE

In 1965, Maine promulgated an act concerning the testing of newborn infants for the detection of metabolic abnormalities which may result in mental retardation. Presently Maine is screening newborns for phenylketonuria (PKU), hypothyroidism, galactosemia, maple syrup urine disease, and homocystinuria.

Newborn Screening Statutes

Title 22 of the revised statute was amended to add a new Section 1522, authorizing the Maine Department of Health to require hospitals, maternity homes, and other maternity services to be responsible for the testing of newborn infants for those metabolic abnormalities that cause subsequent mental deficiencies.

Pursuant to this law the department may enact rules and regulations to define this requirement including the approved test methods, materials, and timing. In accordance with these rules and regulations, the department may require that reports and records of the testing be submitted to it. On request, the department may offer consultation, educational, and evaluation services to the facilities performing the tests.

Should the parents of the newborn object to the tests on religious principles, testing will be waived.

Administrative Regulations

To date, the department has established no rules or regulations relating to the statute.

The new paragraph 40129.2 stipulates that any of the persons named in this section, departments, and agencies of the state and of the counties, municipalities, and other political subdivisions that are capable of assisting the Department of Health and Human Resources in the provision of services to children may cooperate with the department and may furnish any such services and facilities.

Section 40129.3 requires the cooperation of physicians and hospitals within the state that provide obstetric and pediatric care to give the established program of the department.

Administrative Regulations

The department has not promulgated formal regulations.

Other Relevant Laws or Regulations

Section 40129.4 provides for the establishment and operation of centers for research with the Louisiana State and Tulane University Medical School for the treatment of sickle cell anemia. These centers authorized by the Department of Health and Human Resources shall be located in a hospital or part of a hospital in New Orleans and Mary P. Long Charity Hospital, Pomfret. The centers shall meet all criteria with sickle cell anemia with regard to the state's minimum requirements of a charity hospital in the program, and retention of the patient's funds. The centers shall also be the sites for the training of physicians and medical students in the management of sickle cell anemia.

In reference to the testing program for these metabolic disorders, and congenital diseases, the law of Louisiana does not allow anyone employed by the state to be any public or private health care agency that is a component of government machinery to oversee or administered that any woman have an abortion. This law, Section 40129.14, does not apply to abandoned physicians who may be acting to preserve the life of the pregnant woman.

The state of Louisiana has also promulgated a law relating to sickle cell anemia with respect to school-age children. Louisiana Revised Statute 17:41 states that in addition to screening each school-age child for the first time, must provide satisfactory evidence of being in better than the sickle cell anemia. When at its level, the student will be given a sickle cell anemia, unless parent or guardian provides for the testing of the child by a private physician or public health unit where the school is located.

If a child is participating in a school activity from within or without Louisiana, a certificate of status in indicating the performance of a sickle cell anemia test on the child must be submitted.

If the results of the test are positive at home, the private physician or public health unit must submit written documentation of this result to the school, board of the city or parish where the child lives. The information of the result may also be sent to any administrative organization to the public school board or appropriate governing body of the school in a district that is a center of kindergarten.

MARYLAND

In 1973, the Maryland legislature established the Commission on Hereditary Disorders to set standards for the state's programs on genetic diseases. Under the authority granted it by statute, the commission has promulgated regulations governing screening programs and other state activities related to genetic diseases. At this time, newborn infants are screened for phenylketonuria (PKU), hypothyroidism, maple syrup urine disease, homocystinuria, and galactosemia. Maryland has also enacted a statute that prohibits insurance companies from discriminating against persons who have genetic traits that are harmless in themselves.

Newborn Screening Statutes

Sections 814 to 821 of Article 43 of the Annotated Code of Maryland establish the Commission of Hereditary Disorders and describe the powers of the commission. Section 817(a)(1) gives the commission the power to establish rules, regulations, and standards for the detection and management of hereditary disorders.

Section 818 lists the principles that shall govern the rules established by the commission. Among the principles established here are the voluntary nature of the testing programs, the confidentiality of information about particular individuals participating in the programs, the requirement that participants be fully informed of risks and benefits, and the rights of individual participants, or their parents or guardians, to be informed of unambiguous test results.

Section 820 gives the secretary of health and mental hygiene the responsibility to operate the state's programs within the standards set by the commission, to enforce the rules of the commission, and to inform the commission of the progress of programs and of any need for changes in the rules.

Administrative Regulations

The Commission on Hereditary Disorders has promulgated regulations governing the administration of newborn screening programs. In the Code of Maryland Regulations 10.38.01, the commission specifies the diseases to be tested for, the persons responsible for the testing, the laboratory, referral and reporting procedures to be followed, the counseling to be offered to parents or guardians, and the records to be kept.

The regulations specify that all newborns in the state shall be tested, unless the parent or guardian objects. The test shall screen for PKU, maple syrup urine disease, and any other hereditary metabolic disorders specified by the Department of Health and Mental Hygiene with the approval of the commission. Presently in addition to PKU and maple syrup urine disease, hypothyroidism, galactosemia, and homocystinuria are being screened in newborn infants.

The person in charge of the institution where the child is born is responsible for seeing that the screening test is administered. If the child is born outside an institution, the responsibility for having the screening test administered rests with the individual required to file the certificate of birth. In either case, the written approval of the parent or guardian must be obtained before the test is administered.

The regulations strongly recommend that a second test be administered before the child is 4 weeks old. Oral or written consent of the parent or guardian should be obtained for the second test.

The regulations specify that the laboratory analyses shall be performed by the department or by a laboratory approved by the department and the commission. All specimens shall be forwarded to the laboratory within 24 hours after collection. The laboratory will report the results to the appropriate institution or physician within 7 days after receiving the specimen.

The director of every laboratory performing analysis of these specimens will notify the department, within 1 week of receiving the specimen, of every abnormal test result. The department will follow up every abnormal test result by contacting the appropriate individual or institution, which shall try to obtain a second sample. If the parent or guardian fails to respond to the request for a second test, the department will be informed and will try to notify the parent or guardian of the importance of a follow-up test. If a follow-up test establishes the presence of a metabolic disorder, the department will notify the physician or local health department and will recommend sources of treatment.

The department will provide counseling to any parent or guardian requesting it. The counseling shall be informative and nondirective.

The department will maintain a register of every newborn diagnosed as having a hereditary disorder. The records shall be held confidential.

Other Relevant Laws or Regulations

Section 223(a)(3) and Section 223(b)(4) of the Annotated Code of Maryland prohibit insurers from refusing to insure any individual and from making differentials in ratings, premium payments, or dividends in connection with life insurance or health insurance 'solely because' the applicant or policyholder has the sickle-cell trait, thalassemia-minor trait, hemoglobin C trait, Tay-Sachs trait, or any other trait that is harmless within itself, 'unless there is actuarial justification'.

The Commission on Hereditary Disorders, in Code of Maryland Regulations 10.39.02, establishes the procedures to be followed in screening programs for sickle-cell, thalassemia, and related conditions. The regulations state that the screening programs shall present educational information before screening individuals and shall be integrated with other aspects of health care whenever possible. This testing is voluntary, and the 'informed consent' of participants must be obtained and recorded. Results of tests shall be reported to the individual. An individual with a positive test result shall receive counseling and where appropriate referral for follow-up medical care. The confidentiality of individual test results shall be maintained. The regulations also specify the testing procedures to be used and the records to be maintained by screening programs.

MASSACHUSETTS

In 1963 the Commonwealth of Massachusetts established a law mandating testing for phenylketonuria (PKU). This law has since been amended to include infant testing for cretinism (hypothyroidism) and other specifically treatable genetic or biochemical disorders as determined by the commissioner of public health. Recently, this same statute was again amended to add tuberous sclerosis to the group of disorders being screened; however, testing for this disease is not scheduled to begin until 1986, as per the statute. In addition to this law, Massachusetts has enacted a statute prescribing blood tests for sickle cell anemia.

Newborn Screening Statutes

Massachusetts General Laws Chapter 111, Section 110A makes the physician attending a newborn child responsible for the administering of tests for PKU, hypothyroidism, tuberous sclerosis (effective in 1986), and other treatable genetic or biochemical disorders as decreed by the commissioner. This section also stipulates that the commissioner may enact rules pertaining to the tests although at this time no such rules have been established.

The provisions of this statute may be waived should the parents of a child object to the testing on religious grounds.

As a result of this statute, Massachusetts tests newborn children for the following disorders: PKU, galactosemia, homocystinuria, maple syrup urine disease, hypothyroidism, and other amino-acid and organic acid disorders. Mothers are screened, at the time of birth, for maternal PKU and maternal histidinemia.

Administrative Regulations

There are no formal regulations accompanying the newborn screening statutes.

Other Relevant Laws or Regulations

Massachusetts General Laws Chapter 76, Section 15A dictates that every child whom the commissioner of public health, by rule or regulation, determines is susceptible to the sickle cell trait or sickle cell anemia, shall be required to have a blood test for the disease before admittance to a public school or in the first year of attendance. These rules or regulations shall also prescribe the preparation and distribution of educational materials on the disease.

Chapter 76, Section 15B relates to the screening programs, testing, and treatment of sickle cell anemia and other similar genetically-linked diseases. This statute states that the Department of Public Health shall supply necessary laboratory and testing facilities for the voluntary sickle cell anemia screening programs and other genetically-linked diseases such as Tay-Sachs, Cooley's anemia, and hemophilia as may be determined by the commissioner. These programs, if determined to be necessary, shall be established by each city and town. The commissioner shall institute rules and regulations for the testing, treatment, care, and counseling of all susceptible individuals.

This program as established must include provision for a complete health education and post-screening counseling service and treatment for those affected by any blood abnormality, as deemed appropriate or practical by the commissioner. Records kept as part of these programs must be confidential and not accessible to anyone other than the commissioner or his agents, and the local health departments. The results of the tests may be released to the parents if the child is under 18 years of age or to the individual himself if he is over 18 years old.

This statute has, to date, not been fully implemented and no regulations have been promulgated. Testing for sickle cell trait is performed by the Boston Sickle Cell Center and the Tay-Sachs Prevention Program of New England screens for Tay-Sachs disease.

MICHIGAN

Michigan has one law in effect requiring the testing of infants for the detection of phenylketonuria (PKU) and other handicapping conditions. Pursuant to this law, the state has enacted regulations that specifically outline the methods of implementation of the PKU statute. Additionally, Michigan provides hypothyroidism screening of newborns on a voluntary basis.

Newborn Screening Statutes

Section 5431 of the Public Health Code for Michigan dictates that a health professional in charge of the care of a newborn or the health professional in charge of the infant's birth must ensure that tests for PKU and other handicapping conditions as designated by the Department of Health are performed on the newborn infant. This health professional must report the results of a positive test to the infant's parents, guardian, or person acting in loco parentis.

The timing and procedures for the test are under the authorization of the Department of Health. The department may also implement regulations prescribing the testing for additional chronic diseases.

A violation of this code section or of a regulation promulgated under it constitutes a misdemeanor punishable by law.

Administrative Regulations

Regulations 325.1471 to 1475 pursuant to the code authorize the utilization of the Guthrie test at no charge by the Department of Public Health. Other tests may be permitted under controlled research conditions provided a written application has been made and written approval given by the state health director.

These regulations, mandated in 1965, describe the timing to be employed in the screening procedures and the standards for quality control to be used by the laboratories analyzing the test specimens. The laboratories must report any presumptive positive test immediately by telephone to the responsible physician and by telephone or telegraph to the office of the state health director, and a second specimen must be requested to be submitted within 72 hours. No therapy should be begun until a diagnosis confirming the presence of disorder has been determined. A written report of all tests must be made to the responsible physician through the agency submitting the specimen.

Other Relevant Laws or Regulations

Though no other laws have been mandated relating to the screening, treatment, and research of human genetic diseases, the State of Michigan has demonstrated a strong, growing commitment to ameliorating the effects of genetic diseases. In addition to requiring testing for PKU, Michigan has adopted a voluntary program to screen for hypothyroidism, tests targeted risk populations for sickle cell anemia, providing counseling when indicated. Michigan has also created regionalized systems for intensive care treatment for children diagnosed with PKU, training for the neurologically handicapped, and services for children with crippling conditions including hemophilia, cystic fibrosis, and other genetic diseases.

In 1978, the state initiated its greatest endeavor to counteract the deleterious effects of genetic disorders with the creation of the Michigan Genetic Disease Plan. This plan provides genetic, diagnostic, therapeutic, and counseling services to all state residents who require them.

MINNESOTA

The State of Minnesota has enacted a series of statutes that establish tests for inborn errors of metabolism, investigative studies in the field of human genetics, and a cytogenetics laboratory for the study of human chromosomes for diagnosis of hereditary diseases. Minnesota has also promulgated rules and regulations relating to the testing of infants for metabolic disorders.

Newborn Screening Statutes

Minnesota Statutes Section 144.125 (1974) prescribes tests of infants for inborn errors of metabolism causing mental retardation. Each infant in Minnesota must be screened for phenylketonuria (PKU) and other metabolic diseases in accordance with the rules and regulations dictated by the State Board of Health. The administrative officer or other person managing each institution caring for infants and the person required to register the child's birth as per the Minnesota statutes on birth registration are responsible for the testing. The statute does not apply to any infant whose parents find the testing or treatment contrary to their religious tenets and practices.

Administrative Regulations

Chapter 11, 7 MCAR Section 1.172, Department of Health, Rules Relating to Tests of Infants for Inborn Metabolic Errors Causing Mental Retardation, describes the responsibilities of the hospitals, physicians, and the Department of Health to ensure that all infants are screened for PKU, galactosemia, and hypothyroidism.

The responsible parties in the testing program are the administrators of the hospital where the child is born, and the physician or other person operating under the supervision of a physician in attendance at the birth. If not so attended, the child's parents are deemed the responsible persons for the purposes of the testing.

The duties of the responsible parties include: (1) informing the parents or legal guardian of the nature of screening procedures to be performed on their infant, the reasons for such screening, and their right to be exempt from the testing on religious grounds; (2) causing the collection of the testing specimen after the infant's birth; (3) recording on a permanent record the date the specimen was procured; and (4) sending the specimen and specifically defined information on the infant to the Minnesota Department of Health Laboratory. In the event of a confirmed positive diagnosis for PKU, galactosemia, or hypothyroidism, the attending physician must send a written report to the Human Genetics Unit of the department. This duty may be delegated to a medical specialist if the physician has referred a patient to such a specialist for diagnosis and treatment.

The department must maintain a record of all reported cases of PKU, galactosemia, and hypothyroidism. The department must also notify the attending physician within 24 hours verbally and in writing by first class mail of a positive result and provide consultation on the available diagnostic and treatment sources.

Other Relevant Laws or Regulations

Minnesota Statutes Sections 144.91 to 144.94 (1974) contain provisions for the institution of programs to study human genetics and the diagnosis of hereditary disease.

The State Board of Health is authorized by Section 144.91 to implement and maintain a program on human genetics. This program includes the collection and interpretation of information relating to human hereditary diseases and pathologic conditions; the collation, preparation and distribution of data-based materials on the subject for both professional counselors and the public; the performance of investigative studies to potentially reduce the frequency of manifestation of the various deleterious genes; and finally, the provision of counseling services for the public. The board shall enlist the cooperation of the University of Minnesota, the Public Health Service, and the Children's Bureau of the Department of Health and Human Services and nationally recognized scientific professional organizations specializing in problems of human genetics.

The board is also required to implement, staff, maintain, and operate a cytogenetics laboratory for the examination of human chromosomes for the diagnosis and study of hereditary diseases. These laboratory services, as per Section 144.94, are to be provided at no charge to the patient if the board judges the patient to be unable to pay.

Monies for the programs mandated by the human genetics statutes may be received by grants from the Public Health Service or any other federal agency which may appropriate funds for this purpose. Gifts from private organizations and individuals may also be made to the state to be used for the implementation and maintenance of these programs.

MISSISSIPPI

Currently, the State of Mississippi has one law relating to the detection and treatment of genetic and metabolic disorders, which authorizes the State Board of Health to establish a program for combating phenylketonuria (PKU) and hypothyroidism.

Newborn Screening Statutes

Sections 41-21-201 to 41-21-203 of the General Laws of Mississippi (1979) authorize the State Board of Health to establish and maintain a voluntary participation program to prevent the onset of mental retardation in children with hypothyroidism and PKU. To achieve this goal, tests for the detection of diseases, approved by the Board, may be provided by either the physician attending the newborn infant, or the person attending the infant when no physician is present. The State Board of Health must follow up all presumptive positive cases with the physician who informed the board, or with the parents when notification was made by a person other than a physician. The services and facilities of the board and those of other state boards, departments, and agencies cooperating with the State Board of Health in implementing the provisions of this law shall be available to the extent needed by the physician.

The test for PKU and hypothyroidism shall not be given if the parents object to the testing of their child.

Administrative Regulations

The board at this time has not promulgated formal provisions.

MISSOURI

The State of Missouri has enacted one statute pertaining to the testing of infants for metabolic diseases. Pursuant to this law, Missouri has promulgated a series of rules and regulations governing the testing for metabolic disorders. In addition to these laws, Missouri has recently passed hemophilia statutes establishing a program for the care and treatment of persons with this disease. Missouri also has initiated projects for the screening, treatment, counseling, and education of the public for sickle cell anemia and for treatment of cystic fibrosis, though no laws exist, per se, that require these projects. Funding for these programs is provided yearly by the Missouri State Legislature.

Newborn Screening Statutes

Missouri Revised Statutes Section 210.065 dictates that every infant born in the state must be tested for phenylketonuria (PKU) and other metabolic diseases as prescribed by the Division of Health. At present, hypothyroidism is being screened under this statute. It is the responsibility of the parent, guardian, or custodian of the infant to ensure that the attending physician, midwife, public health facility, or hospital performs these tests. These tests may be waived if the parent objects on religious grounds. All positive cases of any of the metabolic diseases, as designated by the Division of Health, must be reported by the physician, public health nurse, or administrator of the hospital to the division.

The division shall develop and implement educational programs on metabolic disorders and screening procedures for physicians, hospital personnel, public health nurses, and the general public. If the parents neglect to have their child tested for PKU or other metabolic diseases after they have been properly notified by the physician of the requirement for the tests, they shall be guilty of a misdemeanor punishable by law.

Administrative Regulations

The 'Regulations Pertaining to the Administration of a Test for Phenylketonuria' describe blood and urine testing methods; quality control; the responsibilities of parents, hospitals, and physicians; and exemptions. Any objection the parents may make on religious grounds must be stipulated in writing and filed in the office of the attending physician, hospital, public health facility, or midwife.

Other Relevant Laws or Regulations

Missouri Revised Statutes Sections 191.330 to 191.340 empower the Division of Health of the Department of Social Services to create a program that financially assists persons who require continuing treatment for hemophilia but who are not able to afford the entire cost of such services after payment of claims from the various kinds of hospital and medical insurance coverage, Medicare, Medicaid and other Federal, state, and private charitable assistance programs. Financial aid will be available to those persons who prove that they have exhausted all benefits from such sources.

Financial assistance will be extended to hemophiliacs for the purposes of obtaining blood, blood derivatives, and other necessary substances for utilization in hospitals, medical and dental facilities, and at home. Monies will also be used to assist in the cost of blood processing that may facilitate the supplying of blood, blood derivatives and other 'efficacious agents' to needy persons at an economical fee.

The Division of Health shall support the implementation and growth of programs for care and treatment of persons with hemophilia. These programs include self-administration, prevention, home care, and other medical and dental procedures designed to best control the disease. The division shall also initiate and maintain educational programs on methods of care and treatment of hemophilia for physicians, dentists, hospitals, public health departments, and the public. The division shall also distribute information concerning hemophilia to those groups.

The division is authorized to promulgate all rules and regulations necessary to implement this statute.

MONTANA

Montana has one statute mandating the screening of newborn children for phenylketonuria (PKU) and other 'aminoacidopathies'. Pursuant to this law, the state has promulgated a series of regulations that detail very closely the duties of the responsible persons in administering the tests and the timing and methods to be followed. Presently Montana is testing newborns for PKU, hypothyroidism, galactosemia, homocystinuria, maple syrup urine disease, and tyrosinemia.

Newborn Screening Statutes

Section 50-19-203 of the Revised Codes of Montana Annotated requires that the administrator of the facility where a child is born or of the institution where an infant receives perinatal care, or the individual responsible for the registration of an infant's birth shall ensure that a test designed to detect inborn errors of metabolism is given to the child. These tests shall be analyzed by a state laboratory or any other laboratory approved by the state. The Department of Health may promulgate rules and regulations to implement the provisions of this statute.

Administrative Regulations

The regulations listed in Montana Administrative Code 16-2.18 (6)-S1820 provide for the screening of all infants for inborn errors of metabolism, including PKU and other aminoacidopathies. The persons managing any facility for newborn infants and those individuals responsible for the registration of births must assure that each infant has been screened. These persons must be certain, prior to the infant's discharge, that the specimen is forwarded to the appropriate laboratory and a record of the testing date and the results made on the infant's medical chart.

In the event that a newborn is discharged from an institution prior to the third day of his or her life, the administrative officer or other person in charge of the institution must make provisions at the time of discharge for the proper testing of the newborn. At this time, the parent or legal guardian must be required to sign a statement assuming responsibility for the subsequent testing of the child. Special provisions are made in the regulations for the timing of screening procedures for those infants born prematurely or transferred from one institution to another after birth. If the infant was born outside a hospital and has not been admitted to a hospital for newborn care, the duty to see that the screening is done rests with the person responsible for registering the birth.

The laboratory tests to be utilized must be approved by the Montana Department of Health and must comply with Sections 69-6710 through 69-6713 of the Revised Codes of Montana. The laboratory analyzing such tests must also be approved by the department. Should the initial test performed be either positive or suspicious for PKU or other related aminoacidopathy, the laboratory must report the finding within 48 hours to the Department of Health. A second test must then be performed immediately. The hospital administrator or person in charge must inform the attending physician of all test results.

NEBRASKA

Currently the State of Nebraska has three acts of statutes that relate to the screening and treatment of genetic diseases. Revised Statutes of Nebraska Sections 71-645 to 71-648 concern the establishment and implementation of programs for the scientific investigation and research on causes, methods of prevention, treatment and cure of birth defects. More specifically, Statutes 71-604.01 and 71-604.3, amended in 1979, provide for the screening of all infants for metabolic disease. At present, infants are being screened for phenylketonuria (PKU) and hypothyroidism. The latest genetic disease act passed by the state, the Genetically Handicapped Person's Act, deals with the adoption of a program for the treatment of individuals with cystic fibrosis, hemophilia, sickle cell disease, and other genetic disorders.

Newborn Screening Statutes

Statutes 71-604.1 and 71-604.3, on screening for metabolic diseases, decree that all infants must be treated for metabolic diseases, which shall include, but not be limited to, PKU and hypothyroidism. The Department of Health may require that testing for any other syndrome be performed and reported on the birth certificate when such screening is perfected according to the standards of proper medical practice. In the event that the parent or guardian of the child objects due to conflicts with the religious practices and principles of an established church of which he or she is an adherent, these stipulations may be waived. The department is authorized to set and enforce rules and regulations to implement this act.

In the case of a positive test for PKU or hypothyroidism, the department is responsible for determining whether the disease is present. The responsibility for the provision of appropriate and necessary follow-up care rests primarily with the parent or guardian of the child and secondarily with the department. They must ensure that those persons tending to the child are fully informed of the accepted medical procedures for the detection, prevention, and treatment of the disease.

Administrative Regulations

At this time, the state has promulgated no formal regulations.

Other Relevant Laws or Regulations

Sections 71-645 to 71-647 empower the Department of Health to develop and carry out investigative programs on the causes, prevention, treatment, and cure of birth defects. The director of the department must create a registry of birth defects to accomplish this task. This registry shall contain inquiries and surveys of the causes, mortality, methods of prevention, treatment and cure. The results of such investigations must be published annually for distribution to scientific organizations, scientists, and physicians.

Section 71-648 concerns the reporting of cases of birth defects to the department. Birth defects and 'allied diseases' must be reported to the department by the physician, hospital, or other persons attending the birth of the infant. Should either of the parents object to such reporting because of religious belief, the requirement of a report will be waived. All reports and information collected will remain confidential and may not be utilized as evidence for the purposes of legal action or proceedings of any kind. Such information may be published for scientific and health reasons provided the identities of these concerned remain unknown.

Sections 68-1401 to 68-1406, known as the Genetically Handicapped Person's Act, provide for the treatment of cystic fibrosis, hemophilia, sickle cell disease, and other genetically handicapping conditions. Persons of all ages may be given any or all of the following: initial diagnostic evaluation; expert diagnosis; aid for the financing of blood transfusions and blood derivatives; rehabilitative services, including reconstructive surgery; medical and surgical treatment; hospital care; physical therapy; occupational therapy; materials and prescription drugs; appliances and their upkeep; and maintenance, transportation, or care necessary in the provision of any other type of service.

Reimbursement shall be made to the extent services are not available to the recipient, or eligible state resident, under any federal, state, or private program or under any contractual or legal entitlement, including insurance. However, this act is not meant to limit in any way state participation in any Federal Government program for Medicare coverage of the genetically handicapped. The Department of Public Welfare is authorized to set standards for financial eligibility for treatment under this program which all county and district health departments shall employ. Included in these standards is a formula for the payment of services by physicians and other health care providers which also applies to all county and district health departments.

NEVADA

The State of Nevada has one statute pertaining to the testing of infants for preventable mental disorders. Pursuant to this statute, Nevada has mandated regulations defining the responsibilities, methods, and enforcement of the screening program. Presently Nevada is screening newborns for phenylketonuria (PKU), hypothyroidism, galactosemia, tyrosinemia, homocystinuria, and maple syrup urine disease.

Newborn Screening Statutes

Nevada Revised Statutes Section 442.115 was enacted in 1967 and amended in 1979 to broaden the law from PKU to include other newborn tests which allow the detection of preventable mental disorders. The tests for these disorders are to be performed by any attending physician, midwife, or nurse at the maternity home or hospital of the child's birth. Should the tests reveal the existence of these diseases, the physician, midwife, nurse, or other hospital or maternity home attendant must report the condition to the local health office for the area where the infant or mother resides and inform those responsible for the infant's care of the necessary treatment. An exemption from testing will be made for any child whose parents object to the testing and file a written statement with the institution responsible for the screening.

Administrative Regulations

'Regulations Governing Metabolic Error Screening of Newborns' provides that: (1) every hospital in the state administer the appropriate blood sample test to all infants born in the hospital; (2) should the infant be born outside the hospital, responsibility for the testing rests with the person who registers the child's birth; (3) should a blood sample be taken prior to discharge but less than 48 hours after the ingestion of milk by the infant, the hospital obtain a statement from the parent or guardian of the child that he or she will have the test performed again between the 7th and 14th day of the infant's life; (4) a positive or questionable test dictate a second blood sample be taken by the child's physician; (5) the parent or guardian of the child with a positive or questionable test promptly refer the child to a physician for further quantitative evaluation; (6) a recording be made in the infant's medical chart of the date the sample was taken and a follow-up test form be completed and signed by the parent or guardian; and (7) the above provisions be waived and a written statement be filed by the parent who objects to the testing with the person or institution responsible for the testing.

NEW HAMPSHIRE

In 1965, New Hampshire enacted three statutes on phenylketonuria (PKU) detection. At present, along with the testing for PKU, the examination for hypothyroidism is provided on a voluntary basis, though no law mandates this activity. Legislation on hemophilia was promulgated by the state in 1977. The most recent law relating to hereditary disorders became effective on July 1, 1979; it concerns the extension of crippled children's services to adults with cystic fibrosis.

Newborn Screening Statutes

Under New Hampshire Revised Statutes Annotated Section 132:10-a,b,c, testing for PKU is required for all newborn children in the state. The physician or hospital attending the baby is responsible for the testing. To implement this program, the director of the Division of Public Health Services is empowered to design necessary rules and regulations. The testing requirement is waived if the parents of a child object.

Administrative Regulations

The state has promulgated no formal regulations at this time.

Other Relevant Laws or Regulations

New Hampshire Revised Statutes Annotated Section 137-E:1 to 4 establishes a program to assist hemophiliacs who require continuing treatment with blood and blood derivatives. The director of the Division of Public Health Services of the Department of Health and Welfare is authorized to: (1) develop and issue standards, rules, and regulations for determining eligibility for treatment under the program; (2) assist in the generation and enlargement of care and treatment programs for hemophiliacs, including self-administration, prevention, home care, and other techniques intended to provide the maximum possible control over the disease; (3) provide financial aid to those with hemophilia who require such help; (4) participate in the cost of blood processing; and (5) establish and maintain educational programs for health care providers and the public on the methods of care and treatment for hemophilia.

The director shall determine the extent of financial assistance to be given to any individual eligible resident of the state. If in any particular year the amount of funds needed exceeds the available monies, the director must prorate such funding so that all persons receive the same proportion. To ease this problem, the director is instructed to apply to the Federal Government for aid under the authorization of Federal funding to individual states for hemophilia.

Sections 270:1 to 270:3 decree that the director of the Division of Public Health Services, Department of Health and Welfare, shall provide the assistance of the crippled children's services to persons 21 years of age or older who are afflicted with cystic fibrosis. These services must be offered with the same conditions, requirements, and criteria applying to persons under 21 years of age. This statute appropriates approximately \$65,000 for the fiscal year ending June 30, 1980 and a similar sum for the next fiscal year to the division for these services. This law further stipulates that \$53,000 must be spent for medical benefits and the remaining \$12,000 for personal services.

NEW JERSEY

New Jersey has a variety of laws concerning genetic and metabolic diseases. The state has enacted statutes that mandate the screening of newborn infants for phenylketonuria (PKU) and hypothyroidism and the appropriation of monies for sickle cell anemia, Cooley's anemia, and Tay-Sachs disease programs. New Jersey has also promulgated a statute establishing a program for the care and treatment of hemophiliacs, and one that concerns the issuance of marriage licenses. Additionally, a law exists that requires that the birth of any child born with a visible congenital deformity be reported to the Commission of Health.

Newborn Screening Statutes

Chapter 268 of the Laws of New Jersey, 1964, provides for the testing of newborn infants to detect the presence of PKU and appropriates funds for this purpose. In order to prevent the onset of mental retardation every newborn child should be given a PKU test approved by the State Department of Health. This provision may be waived for infants whose parents object on religious principles. The department shall implement and maintain laboratory services, as are determined necessary by the Public Health Council, and an educational and training program on PKU designed for physicians, hospital staff, public health nurses, and the public. The state commissioner of health shall make rules governing the procedure for submitting specimens to the state laboratory, which may charge fees for the laboratory analysis.

Chapter 321 of the Public Laws of 1977 mandates the establishment of newborn testing for hypothyroidism and makes an appropriation of monies for the testing. Every newborn should be given a department-approved test for the detection of hypothyroidism. A newborn infant whose parents object for religious reasons to the screening may be exempt from the procedure. The state laboratory shall perform the analysis of the tests. The department shall institute and maintain an educational program on hypothyroidism geared to the same population and with the same goals as the PKU program. The commissioner of health is empowered to implement a program for reviewing and following up on all positive cases in order to prevent mental retardation.

Section 9:13-5 of the Revised Statutes requires that within 30 days of the birth of a child in this state with a visible congenital deformity, the attending physician, midwife, or other person acting as a midwife shall file a statement of this deformity with the Commission of Health. This statement shall be used solely by the commission for the care and treatment of crippled children and shall not be open to public inspection nor considered public record.

Any person violating this provision shall be subject to a penalty of \$50.

Administrative Regulations

At this time there are no formally promulgated regulations.

Other Relevant Laws or Regulations

Chapter 241 of the Public Laws of 1975 (sickle cell anemia), Chapter 142 of the Public Laws of 1978 (Cooley's anemia) and Chapter 150 of the Public Laws of 1978 (Tay-Sachs disease) deal with county assistance for the care of children suffering from these diseases. These laws give the governing body of a county that has no home or hospital for children with these diseases the right to spend a certain amount of money annually to diagnose and treat children resident in the county. The Cooley's anemia and Tay-Sachs disease statutes also mention that a certain sum of money may be spent annually to (1) promote public awareness among prospective parents as to the importance of testing for these diseases and (2) create a referral service for individuals to be tested for the disorders and, in the case of a county which has no facility suitable for the treatment of such diseases, to cover the expense of diagnosis and treatment.

All three statutes dictate that, before any expenses may be incurred, the governing body of a county must make rules and regulations as it deems necessary to determine eligibility for such assistance.

Chapter 282 of the Public Laws of 1977 requires that a licensing officer or other person issuing marriage licenses shall make available to applicants information on where they may be tested for certain genetic traits. These traits include, but are not limited to, Cooley's anemia, sickle cell anemia, and Tay-Sachs disease.

New Jersey Revised Statutes Sections 26:2-90 to 26:2-93 empower the State Department of Health to establish a program for the care and treatment of persons suffering from hemophilia. This program shall aid persons who need continuing treatment with blood and blood derivatives and intensive hospitalization but who are unable to finance the entire cost of such services despite the existence of various types of insurance coverage and assistance programs.

The department shall (a) implement criteria for eligibility under this program; (b) assist in the development and growth of programs for the care and treatment of hemophiliacs, including self-administration, prevention, home care, and other medical and dental procedures aimed at achieving maximum control over the disease; (c) extend financial support to hemophiliacs in order that they may obtain blood, blood derivatives and other necessary agents, or join in the cost of blood processing to the extent that this assistance will facilitate the supplying of the above needed substances at an economical cost; (d) institute and maintain educational programs concerning the methods of care and treatment of hemophilia for physicians, dentists, hospitals, public health departments, and the public; and (e) enact regulations necessary to accomplish the goals of this statute.

New Mexico Statute 1979, Chapter 100, Section 10-10-1. The purpose of the Department of Health and Human Services is to provide for the health and safety of the people of the state. The department shall develop and maintain a comprehensive health care system for the people of the state. The department shall also develop and maintain a comprehensive system of health care services for the people of the state. The department shall also develop and maintain a comprehensive system of health care services for the people of the state.

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New Mexico has adopted one statute that concerns the testing of newborns for the detection of phenylketonuria (PKU) and other congenital diseases. The statute also authorizes the promulgation of regulations applicable to the newborn screening program.

New Mexico Statutes Annotated Section 24-1-6 establishes that tests for PKU and other congenital diseases be given to every newborn in the state. The secretary of the Department of Health and Environment shall consider the recommendations of the New Mexico Pediatrics Society in determining which congenital disorders should be screened.

The department shall institute and maintain laboratory services, or may contract with another agency or state to provide those services necessary to analyze the test specimens. Testing for congenital diseases other than PKU depends upon the availability of funding from sources other than state appropriations.

Administrative Regulations

The regulations require tests for PKU, hypothyroidism, galactosemia, homocystinuria, maple syrup urine disease, and sickle cell anemia. Any other congenital disease for which testing may hereafter be mandatory may be approved by the department on the basis of a formal recommendation made to the department by the New Mexico Pediatrics Society.

A positive or questionable test result must be reported immediately by the regional screening program to the department's Child Development Center and directly to the physician. The parents must be contacted and this contact reported to the hospital and physician for placement in the child's record.

New York has one law that mandates the testing of newborn infants for various genetic and metabolic diseases. New York has promulgated a series of regulations, as authorized by this law, establishing the specific procedures and timing to be employed in the testing. Presently New York is screening for phenylketonuria (PKU), hypothyroidism, galactosemia, maple syrup urine disease, homocystinuria, adenosine deaminase deficiency, histidinemia, and sickle cell disease. In 1974, an additional law was enacted creating the Birth Defects Institute.

Newborn Screening Statutes

Section 2500(a) of the Public Health Laws of New York requires the screening of every infant born in New York for the detection of PKU, sickle cell disease, hypothyroidism, branched-chain ketonuria (maple syrup urine disease), galactosemia, homocystinuria, adenosine deaminase deficiency, histidinemia, and other such diseases and conditions as may be specified by the commissioner of health. The administrative officer or other person in charge of each institution caring for newborn infants and the person required to register the birth of a child must cause every child in his or her care to be tested.

Administrative Regulations

Sections 69.1 to 69.4 of the Administrative Rules and Regulations (Health) describe the test procedures, timing, and the duties of the responsible persons in the screening of infants for the above diseases. The regulations dictate that every infant must be tested for the named metabolic diseases. If the infant is transferred from one institution to another, the tests must be performed prior to discharge to the second institution. In the event that the infant has been born outside an institution and has not been subsequently admitted to an institution for newborn care, the responsibility for the testing rests with the individual required to register the birth. The administrator of the responsible institution and the person required to register the birth of an infant must make sure that a specimen is forwarded to a laboratory for adequate analysis within 24 hours after it has been taken. These parties must, in addition, ensure that information concerning the date of the tests and the results of the tests be recorded on the infant's charts.

The testing requirements may be waived for any infant whose parent or guardian is an adherent of a recognized religious organization whose tenets and customs conflict with the tests. The parent or guardian must notify the person charged with the administration of the tests of his or her objection.

Other Relevant Laws or Regulations

Sections 2730 to 2733 of the Public Health Laws of New York establish a Birth Defects Institute. These sections dictate that the commissioner of health shall establish a birth defects institute within the Department of Health. This institute shall conduct investigations into the causes, prevention, treatment, and cure of birth defects and genetic and allied diseases. Periodically, the commissioner must publish the results from such investigations and collate them for dissemination to the scientific community. The commissioner must also implement educational programs designed for medical students, physicians, nurses, scientists, and technicians in the nature, treatment, prevention, and cure of birth defects and genetic and allied diseases. In addition, the commissioner must conduct and support clinical counseling services in medical facilities.

Section 2733 contains provisions relating to the reporting of birth defects and the confidentiality of such information. Birth defects and genetic and allied diseases must be reported by physicians, hospitals, and persons attending the births in the manner prescribed by the commissioner. This information must be kept confidential and may be used only for scientific and public health purposes in which the identities of the individuals concerned cannot be ascertained.

NORTH CAROLINA

North Carolina has established by administrative regulation a voluntary program for screening newborns for phenylketonuria (PKU), galactosemia, and tyrosinemia. The PKU program is well established and has almost complete participation; a hypothyroidism protocol is currently under study. In addition, North Carolina has adopted statutes and regulations concerning the prevention, detection and treatment of sickle cell anemia, and the employment and insurance coverage of those who possess the sickle cell trait.

Newborn Screening Statutes

There are no formal statutes at this time concerning the screening of newborns for genetic disorders.

Administrative Regulations

Section .0300 of the North Carolina Administrative Code mandates the voluntary newborn screening program in North Carolina. This program screens for the detection of PKU, galactosemia, and tyrosinemia. Agencies and physicians may request analysis of their patients' specimens by the program. Guidelines are given for complying with the code.

Other Relevant Laws or Regulations

General Statutes 143B-188 to 143B-196 establish a Council on Sickle Cell Syndrome appointed by the Governor to advise the North Carolina Department of Human Resources regarding the creation of programs and regulations for education, voluntary testing, and counseling on this disease and related disorders. In addition, the council shall make recommendations for legislative action concerning sickle cell syndrome and related genetic disorders. Representatives from these areas shall be chosen to compose this council: (1) community foundations concerned with sickle cell syndrome and other related disorders; (2) public health departments, on the state, local and Federal levels, interested in rehabilitation and social services; (3) universities and hospitals; (4) state and local school boards; and (5) sickle cell patients and their relatives.

The council shall assess the needs of North Carolina concerning (1) education of the public relative to sickle cell syndrome and other similar genetic disorders; (2) available personnel and facilities for the treatment of patients with sickle cell syndrome and related genetic disorders; (3) payment mechanisms for the medical expenses incurred by patients with these diseases; (4) rehabilitation of patients with these diseases; (5) discrimination against patients with sickle cell syndrome in employment, insurance, and other areas; (6) founding of centers for testing for sickle cell syndrome and related genetic disorders; (7) special counseling and education for those tested at such centers; (8) investigative research into the diagnosis and treatment of sickle cell syndrome and similar hereditary disorders; and (9) scrutiny of present organizations involved with sickle cell disease. This statute authorizes the secretary of human resources to implement pilot programs for education, voluntary testing, and counseling about sickle cell syndrome and related genetic disorders. If, during this program, an individual is found to have any form of the sickle cell syndrome or a related genetic disorder, it shall be the responsibility of the local health department to inform the individual of this finding. It shall be the duty of the North Carolina Department of Human Resources to make testing and counseling available without cost to any person who requests such services. Any program for voluntary testing shall commence only after an adequate educational program has been in effect at least 60 days. Counseling may be done only by persons properly trained and certified in accordance with criteria established by recognized authorities in the field of human genetics.

Section 58-251.6 of the General Statutes states that no insurance company licensed in North Carolina shall refuse to issue or deliver any policy that is currently being delivered in the state and that extends coverage for any medical treatment or service, because the individual to be insured possesses the trait for sickle cell or hemoglobin C. No policy in the state may carry a higher premium rate or charge because the person to be insured possesses these traits.

Section 57-7.1 of the General Statutes establishes that no hospital, medical, dental, or any health service shall refuse to issue or deliver any hospital, dental, medical, or health service contract in North Carolina that it is currently issuing or delivering in this state, which covers any medical treatment or service, because the person to be insured possesses sickle cell trait or hemoglobin C trait, nor shall any such policy issued and delivered carry a higher premium rate or charge because of this trait.

Section 58-195.5 mandates that no insurance company licensed in the state shall refuse to insure or deliver any policy of life insurance because the person to be insured possesses sickle cell trait or hemoglobin C trait; nor shall any such policy carry a higher premium rate or charge because the person to be insured possesses these traits.

Section 95-28.1 states that no person, firm, corporation, unincorporated association, state agency, unit of local government, or any public or private entity shall deny employment to any person or discharge any individual from employment because he or she possesses sickle cell trait or hemoglobin C trait.

Section .0107 stipulates that blood collected through the screening program must be mailed within 3 days of collection. Section .0108 states that specimens are usually tested and reported the day they are received in the laboratory. Section .0105 mentions that, in the testing process, the North Carolina program uses the state laboratory.

Section .0200 of the Administrative Code mandates the North Carolina Voluntary Genetic Counseling Program for families or individuals who are at risk for some type of genetic disorder. Three major components of the program exist: (a) clinical diagnosis, including physical examination and family pedigree; (b) laboratory services, including chromosome and biochemical studies and prenatal diagnosis; and (c) educational and training services aimed at professional groups who may need to refer patients with genetic disorders.

NORTH DAKOTA

In 1967 the legislature of North Dakota enacted statutes that establish educational programs and testing for phenylketonuria (PKU). Presently North Dakota screens newborns for PKU and hypothyroidism.

Newborn Screening Statutes

North Dakota Century Code Section 25-17-01 provides for the development and maintenance of educational programs relating to PKU and to other metabolic diseases which may cause mental retardation. These courses are designed for the instruction of physicians, hospital staffs, public health nurses, and the general public. This statute also dictates the establishment of state-wide screening, and diagnostic and treatment control tests for PKU and other metabolic diseases causing mental retardation, provided that approved laboratory procedures are available.

Section 25-17-02 states that the State Department of Health shall establish standards and methods of testing to be employed for PKU and other metabolic diseases.

In the event of a positive diagnosis for PKU or other metabolic diseases, the department, as stated in Section 25-17-03, must confer with the infant's attending physician to determine the exact diagnosis. The department then must make arrangements for the provision of necessary treatment if the child's family is unable to absorb the cost of treatment. In addition, the department must initiate and maintain a registry of cases of PKU and other metabolic diseases.

Section 25-17-04 places the responsibility of screening newborns on the attending physician and requires him to report any positive test to the department. This statute, however, waives the above stipulations if the parents of the newborn object to the testing on religious grounds.

Administrative Regulations

No formal regulations have been promulgated at this time.

OHIO

The State of Ohio has enacted a number of laws that relate to the detection, prevention, and treatment of genetic diseases. Ohio Revised Code Sections 3701.501 and 3701.502, recently amended in the 1979-1980 Regular Session, mandate testing of newborn children for the early detection of genetic, endocrine, and metabolic disorders. Presently testing of newborns is being done to screen for phenylketonuria (PKU), hypothyroidism, homocystinuria, and galactosemia. Ohio has also passed Section 3701.131, which deals with the causes, detection, treatment, and rehabilitation of persons with sickle cell disease. Section 3701.023 is concerned with the extension of treatment to persons over 21 years of age with sickle cell anemia or cystic fibrosis. Finally, Section 3701.144 establishes a hemophilia program within the Department of Health.

Newborn Screening Statutes

Under Section 3701.501 of the Ohio Revised Code, the person required to file a certificate of birth is also responsible for the testing of each newborn to detect the following diseases: PKU; homocystinuria; galactosemia; hypothyroidism; and any other genetic, endocrine, or metabolic disorder that may be designated by the public health council in the future. The council shall also prescribe rules for laboratory procedures and other methods to be used in the implementation of this testing program. The provisions of this statute do not apply to those children whose parents object to the tests on religious grounds.

Section 3701.502 authorizes the director of health to encourage and assist in the development of programs to detect and treat genetic diseases and educate the public about these disorders. In addition, the director may foster the implementation of programs for the habilitation or rehabilitation and counseling of persons with a genetic disease or a genetic trait for such a disease.

The director shall also consult, advise, and cooperate with, by contract or otherwise, agencies of Ohio, the Federal Government, other states, private corporations, associations, and organizations in the development and promotion of projects concerned with identifying the cause and effecting the detection and treatment of genetic diseases and the habilitation or rehabilitation and counseling of persons with such diseases or traits.

To implement the stipulations of Section 3701.502, the director of health may accept and administer grants from the Federal Government or other sources, public or private.

Administrative Regulations

At this time, the state has promulgated no formal regulations.

Other Relevant Laws or Regulations

Section 3701.131 of the Revised Code of Ohio empowers the director of health to: (1) encourage and support the development of programs of research and education concerning the causes, detection, and treatment of sickle cell disease and plans for rehabilitation and counseling of persons with this disease; (2) advise, assist, and associate with agencies of the State of Ohio, other states and their political subdivisions, the Federal Government, and private organizations and corporations, in the development and promotion of these programs; and (3) accept and manage grants from the Federal Government and other sources, public or private, to fund the various programs.

Section 3701.023 of the Revised Code of Ohio authorizes the Bureau of Crippled Children's Services to provide, at no financial burden to the recipient, diagnostic treatment and supportive services to crippled children under 21 years of age, and to those persons 21 or more years of age suffering from sickle cell anemia or cystic fibrosis. Those persons 21 years of age or older who are eligible for the crippled children's services provided by this statute are liable for as much of the expense incurred as they are deemed able to pay. Determination of ability to pay is made by the Bureau of Crippled Children's Services under rules of the Public Health Council. No parent may be held liable for the debts for these services incurred by persons 21 years of age or older.

Under Section 3701.144 of the Revised Code, the director of health is authorized to establish a program for the care and treatment of persons with hemophilia. He may create a blood donor recruitment program to assist persons who need continuing treatment with blood and blood derivatives in order to avoid the dangerous debilitating effects of this condition. The program also provides medical care and financial aid for hemophiliacs who are unable to afford the cost of their medical expenses despite the various types of public and private insurance coverage, government assistance programs, and private charities in existence. Standards shall be established by the director to determine eligibility for care, treatment, or assistance under this program.

In addition to the programs already described, the director shall also institute and maintain educational programs for the general public, the medical community, and persons with hemophilia.

OKLAHOMA

At this time, the State of Oklahoma has one statute concerning genetic diseases. In 1965, Oklahoma instituted a law designed to promote the voluntary testing of infants for the presence of phenylketonuria (PKU) and other related inborn metabolic disorders. This statute also authorized the promulgation of rules and regulations specifying the approved tests and the laboratories in which they are to be performed.

Newborn Screening Statutes

Sections 1-533 and 1-534 of the Oklahoma Statutes empower the State Board of Health to create and implement an extensive education program for hospitals, physicians, public health nurses, and the public on PKU and related metabolic disorders. The program includes information concerning the nature of the diseases and the tests for early detection necessary to prevent mental retardation.

The board is also authorized to promulgate rules and regulations pertaining to the tests as accepted medical practice indicates. Currently, tests are performed for the detection of PKU and hypothyroidism. The board may make the testing of infants mandatory if evidence proves that the public has been negligent in voluntarily participating in the program and if the board believes it is in the public interest to do so. The board is authorized to set up laboratory facilities, to use existing facilities, and to approve other laboratories to perform and analyze the tests. A reasonable fee may be charged for this screening program, provided that no child be denied the tests because of an inability on the part of the child's parents or guardian to afford such costs.

The provisions of this statute shall not apply to any infant whose parents find the tests to be in conflict with their religious beliefs and customs.

Administrative Regulations

The Oklahoma State Board of Health has adopted rules and regulations that prescribe the appropriate, medically-approved timing, test procedure to be utilized, and the criteria for choosing the laboratories that will assay the test specimens.

OREGON

Oregon has enacted statutes concerning the screening of infants for metabolic disorders, the recording of cases and the education of health care providers and the public about the disorders. In 1977, the Oregon legislature also passed a law authorizing a program for amniocentesis at the University of Oregon Health Sciences Center. Presently Oregon is screening infants for the detection of phenylketonuria (PKU), galactosemia, hypothyroidism, homocystinuria, tyrosinemia, and maple syrup urine disease.

Newborn Screening Statutes

Oregon Revised Statutes Section 433.285 dictates that all infants before the age of two weeks should be given approved tests for PKU and other metabolic diseases. In the event of a positive test for PKU, the physician, public health nurse, or administrator of the hospital must report the finding to the Health Division. Under Section 433.290, the division must initiate educational programs geared to physicians, hospital staff, public health nurses, and the public concerning PKU and other inborn errors of metabolism. Information on the nature of these disorders and the testing for their detection shall be included as part of this program.

Administrative Regulations

No formal administrative regulations have been promulgated at this time.

Other Relevant Laws or Regulations

It is the policy of the state to encourage amniocentesis. Section 352.058 mandates the establishment of an amniocentesis program by the University of Oregon Health Sciences Center. The center must determine criteria for eligibility, including, but not limited to, (1) women over 35 years of age; (2) women who have previously given birth to a child with Down's syndrome or other chromosome disorder; (3) pregnancies where one parent is a translocation carrier; (4) women who carry an X-linked disease; (5) pregnancies where both parents are carriers of an autosomal recessive disease which may be diagnosed before birth; and (6) pregnancies where the parents already have a child with a neural tube defect.

The Health Sciences Center is also authorized to formulate a graduated fee schedule based upon the patient's financial situation. Transportation costs must be considered in formulating this fee schedule. In addition, the center shall develop and implement a program to educate both physicians and the public concerning the purposes of amniocentesis and its availability within the state. The center shall assure that, along with amniocentesis, genetic counseling will be provided.

Amniocentesis is entirely voluntary. Participation in the program may not be a prerequisite to eligibility for or receipt of any other service or aid from any other program.

The program for amniocentesis is financed by appropriations out of the general fund of the state.

PENNSYLVANIA

Pennsylvania has one law relating to genetic and metabolic diseases. Section 621 of the Pennsylvania Consolidated Statutes concerns the testing of newborns for phenylketonuria (PKU) and for other metabolic diseases which may cause mental retardation or physical defects. Presently tests are given newborns to detect for PKU and hypothyroidism.

Newborn Screening Statutes

Section 621 requires every hospital, institution or practitioner caring for infants to ensure the administration of a test for PKU and other metabolic diseases to every newborn in its or his care. No test shall be performed on any child if the child's parent or guardian objects on religious grounds.

Administrative Regulations

Testing for the detection of PKU and hypothyroidism in newborns is mandated by Pennsylvania Administrative Code Chapters 27 to 29. These regulations stipulate the specific methods for procurement of the specimens to be analyzed, the timing to be employed, and the manner of recording results. The persons or institutions responsible for the collection of these specimens must send them to laboratories approved by the Department of Health within 48 hours of collection.

Prior to the administration of the tests, the facility or practitioner responsible for the care of the pregnant woman shall give her a brochure furnished by the Department of Health explaining the nature of the metabolic diseases being tested for and the screening process itself. If the parent or guardian of the child objects on religious grounds, the health facility or provider shall have the duty to see that the parent's or guardian's objection is recorded in the medical record of the infant.

Test results which do not indicate a metabolic disorder must be sent within 7 days following the day the specimen was received by the laboratory to the person or facility who had obtained the specimen from the infant. In the event that a test is presumptive positive for a metabolic disorder, the health care facility or practitioner to whom the results were reported shall promptly notify the parents or guardian, arrange for further testing and treatment, and enter the reports of the results into the infant's medical record. A confirmatory test specimen is required if the results of any test are presumptive positive.

RHODE ISLAND

At present, Rhode Island has one law that mandates the testing of newborns for the presence of phenylketonuria (PKU). On a voluntary basis through the New England Regional Newborn Screening Program, newborns are also screened for congenital hypothyroidism, homocystinuria, maple syrup urine disease, and galactosemia.

Newborn Screening Statutes

Section 23-12-12 of the General Laws of Rhode Island dictates that the physician attending the birth of a child shall cause the child to be tested for PKU. The Department of Health for the State of Rhode Island shall set rules and regulations relating to this test, as indicated by accepted medical practice. This statute, however, does not apply to children of parents who object to the testing on religious grounds.

Administrative Regulations

At present, Rhode Island has no formal regulations relating to PKU screening.

SOUTH CAROLINA

South Carolina has one law, promulgated in 1976 and amended in 1978, that concerns neonatal testing to detect inborn errors of metabolism. Rules and regulations were adopted in 1979 that specify the test methods to be employed in the neonatal screening program prescribed by this statute. The state also issues official department instructions, approved by the commissioner of the Department of Health and Environmental Control, which specify duties and procedures in greater detail. South Carolina has also established a law mandating the creation of voluntary sickle cell education and prevention programs.

Newborn Screening Statutes

Code of Laws of South Carolina Section 44-37-30 stipulates that every child born in the state must be screened for metabolic disorders. The establishment of rules and regulations is authorized under this statute, and any person who fails to comply with the directives shall be guilty of a misdemeanor punishable by a fine of not more than \$300 or 30 days imprisonment. Children of parents objecting to the test for religious reasons shall be exempt from the provisions of this statute.

Administrative Regulations

Section 61-80 of the Code of Laws of South Carolina contains the regulations that specify tests for phenylketonuria (PKU) and hypothyroidism and describe procedures of the screening program. In accordance with department instructions, the Bureau of Laboratories shall adopt laboratory standards for the performance and interpretation of the tests.

The attending physician is responsible for the collection of a specimen from every child born in a hospital in accordance with department instructions. If for any reason a specimen is not collected, the hospital shall notify the Bureau of Maternal and Child Care. The hospital must also review the patient record of each infant in the hospital no later than 10 days after the child's birth to ensure that a specimen was taken and submitted to the laboratory. If the child is born outside a hospital, the attending physician is responsible for obtaining a specimen from the infant and submitting it to the laboratory on the day of collection. The physician must inform the Bureau of Maternal and Child Care if a specimen is not collected within 3 days of any child's birth. If there is no attending physician, the person in attendance or the parents or guardian must notify the county health department within 3 days of delivery so that a specimen may be obtained. Should the parents object to the test for religious reasons, they must complete the procedure specified in the department instructions.

All tests will be forwarded by the laboratory to the attending physician who must then inform the parents or guardian of the results. The attending physician must notify the Bureau of Maternal and Child Care, which will then notify the parents or guardian, of the results in the event that the infant is no longer under his care. If the laboratory finds that a second test must be performed, the attending physician must collect and submit a second specimen. If a child has an abnormal test result, the attending physician must perform further procedures to make a conclusive diagnosis. If this cannot be done, appropriate medical resources must be contacted or the Bureau of Maternal and Child Care must be notified. When a child is diagnosed as having an inborn error of metabolism, the attending physician must alert the Bureau of Maternal and Child Care. The Department of Health and Environmental Control has written 'Official Departmental Instructions for Screening Infants for Inborn Metabolic Disorders.' These instructions describe in detail the responsibilities of individuals, the test procedure, and services and supplies available from the department.

Other Relevant Laws or Regulations

Section 6, part 2, Act. 1555 of the General and Permanent Laws of 1972 authorizes the State Board of Health to initiate a sickle cell education and prevention program to be maintained entirely on a voluntary basis. This program shall provide: (1) laboratory testing of black citizens of reproductive age to determine the presence of the sickle cell gene; (2) counseling for those persons found to have the sickle cell trait; (3) referral of persons with sickle cell anemia so that they may obtain adequate medical care; and (4) education of the public about sickle cell disease for the purpose of eradicating any stigma that might be attached to this disease.

SOUTH DAKOTA

The State of South Dakota has enacted one law concerned with screening and treatment for genetic diseases. Presently South Dakota is screening for phenylketonuria (PKU).

Newborn Screening Statutes

Code of Laws of South Dakota Sections 34-24-16 to 34-24-24 require that all infants born in the state shall be tested for metabolic diseases as prescribed by the State Department of Health. These tests shall include, but not be limited to, the testing for excessive phenylalanine in the serum of newborns. The department shall perform the tests or may contract with any qualified laboratory to assay the specimens when facilities are not available for the screening of newborn children for PKU. All results of tests for metabolic diseases in infants must be sent to the department. If the infant was not screened for PKU, the department must arrange for the testing to be performed.

In the event that a screening test reveals that an infant may have PKU, it shall be the duty of the department to prescribe the procedures to be followed to make a positive diagnosis. The department is responsible for following up on the development of all children with PKU or other metabolic disorders to ensure that those persons with the duty to care for the children are fully informed of the appropriate medical procedures for detection, prevention, and treatment of such conditions.

When tests for other metabolic diseases are perfected, the department may require that these tests be administered and the results reported to the department.

These provisions may be waived for any newborn whose parent or guardian objects in writing due to religious conflict and relays this objection to the attending physician or other person responsible for administering the tests.

Administrative Regulations

The statute authorizes the department to issue rules and regulations, which are currently being formulated, to assist in the implementation of the screening program. Additionally, the department is empowered to provide for the development and maintenance of an educational program for physicians, hospital personnel, public health nurses, and the public concerning PKU and other metabolic disorders that may result in mental retardation.

TENNESSEE

In 1968, the General Assembly of the State of Tennessee enacted Sections 53-624 to 53-633 of the Tennessee Code Annotated. These statutes require that every newborn infant be tested for phenylketonuria (PKU), hypothyroidism, and other metabolic defects to prevent the onset of mental retardation, which may result from these disorders. The State Department of Public Health has promulgated rules and regulations concerning the procedure for obtaining, handling, timing, and reporting the tests. Presently Tennessee is screening newborns for PKU and hypothyroidism.

Newborn Screening Statutes

Each newborn must be tested for PKU, hypothyroidism, and other metabolic disorders that may cause mental retardation. The Tennessee Public Health Council shall prescribe the effective tests and proper methods, times, and reporting for this purpose. The commissioner of public health shall designate the person or persons responsible for assuring that newborn children are screened for PKU, hypothyroidism, and other metabolic diseases. Those responsible persons may include: (1) the parents, guardian, or custodian of the child during its first 2 weeks of life; (2) the person required by Tennessee law to file the birth certificate; and (3) any other person or persons deemed appropriate by the commissioner. In the event of a presumptive positive test, it shall be the duty of the department to contact the parent or guardian and to require or perform any additional necessary tests to confirm the diagnosis. The department shall also furnish all physicians, public health nurses, hospitals, maternity homes, and the Department of Public Welfare available information about the nature and effects of PKU, hypothyroidism, and other metabolic disorders causing mental retardation. Testing or medical treatment is not required for children of persons who are members of a 'well-organized church or religious denomination' whose religious convictions are in conflict with medical treatment for diseases or physical defects.

A person responsible for causing an infant to be tested for the named disorders who willfully refuses or willfully fails to have the child tested according to the adopted rules and regulations shall be guilty of a misdemeanor.

Administrative Regulations

Chapter 1200-15-1, Phenylketonuria And Other Metabolic Diseases, of the Rules of Tennessee Department of Public Health, Bureau of Personal Health Services, Division of Preventive Health Services prescribes that: 1) every chief administrative officer of a hospital and the attending physician must submit a specimen of blood to the Division of Laboratories, State Department of Public Health from every infant who has been on milk feeding for 72 hours unless the infant has been discharged before that time, and; 2) every parent, guardian, or custodian shall be responsible for taking the infant to be tested within 2 weeks after birth if the infant was not born in a hospital or was discharged from a hospital within 96 hours after birth.

The chief administrator of each hospital must assure that a pamphlet prepared by the department, explaining the importance of and requirement for the tests, be distributed to every parent of an infant discharged before tests were taken.

Each local health department must assist the state department in contacting all presumptive positive cases for the disorders to confirm or disprove the first test.

Any person, physician, or hospital willfully neglecting or refusing to comply with the provisions of these regulations shall be guilty of a misdemeanor.

Other Relevant Laws or Regulations

Section 5, part 2, Act 155 of the General and Permanent Laws of 1972 requires the State Board of Health to investigate and report on the progress of the state's efforts to eliminate the incidence of the disease. The board shall provide: (1) laboratory testing of blood samples of newborn infants to determine the presence of the disease; (2) counseling for those persons found to have the disease; (3) control of persons who are not found to have the disease; and (4) control of the disease. The board shall also provide for the purpose of establishing the system that will be used to collect the data.

TEXAS

The State of Texas has two statutes concerning heritable diseases: one on phenylketonuria (PKU) and other heritable diseases, and one on hypothyroidism. Besides screening newborns for PKU and hypothyroidism, the state also tests for galactosemia and homocystinuria. In addition, Texas Revised Civil Statutes Annotated Article 3.70.2 refers to insurance coverage for mental illness and retardation and for congenital defects of newborn children.

Newborn Screening Statutes

Under Texas Revised Civil Statutes Annotated Article 4447c as amended by Senate Bill 834 (1979), the Department of Health must establish and maintain a diagnostic laboratory for performing experiments, projects, and procedures important in the development of tests for the early detection, prevention and treatment of PKU and other heritable diseases. The department may also determine the test procedures to be employed and approve any laboratories that wish to perform the tests required under this article. It is the responsibility of the physician or other person attending the newborn infant to insure that the child is given tests for PKU and other heritable diseases. Provisions of the article are mandatory, provided that the parent or guardian of the newborn child does not object on religious grounds. When a positive test is confirmed, the services and facilities of the department shall be available to the physician and patient. The Department of Health and the other departments, boards, agencies, and political subdivisions of Texas will, in cooperation with the attending physician, provide medical, dietary, and related care for needy children.

Under Article 4447c-1, the Texas Department of Health established a program to detect hypothyroidism in newborn children. Pursuant to the article, the department may institute necessary rules to follow any program created. Essentially the standards set for the screening for hypothyroidism are the same as those for PKU testing. The hypothyroidism test, like the test for PKU, is mandatory for all infants, unless the parent or guardian objects for religious reasons. In this situation, the physician or other person responsible for administering the test is not held liable for his or her failure to perform the test.

Administrative Regulations

Texas has not at this time promulgated formal regulations.

Other Relevant Laws or Regulations

Texas Insurance Code Article 3.70-2 dictates coverage for mental illness and retardation when one's insurance policy covers these disabilities even if the support, maintenance and treatment of the illness is provided by a tax supported institution of the state. The article also states that an accident and sickness insurance policy must not exclude or limit coverage of a newborn infant with congenital defects and must not limit the initial coverage of a newborn for a period of time.

UTAH

Utah has one statute concerning the screening of infants for genetic and metabolic disorders. Pursuant to this law, Utah has adopted regulations that specifically outline the procedures to be employed in the screening program. At this time infants are being screened for phenylketonuria (PKU), congenital hypothyroidism, and galactosemia.

Newborn Screening Statutes

Section 26-17-21 of the Utah Code Annotated empowers the Board of Health to establish rules and regulations requiring that every infant be tested for PKU and other metabolic diseases that may cause mental retardation and for which preventive measures and treatment are available. Pursuant to Item 190 of the Appropriations Act of 1978, the Division of Health shall charge a fee for this metabolic screening program.

Administrative Regulations

The rules and regulations pertaining to the testing of infants for PKU and other metabolic diseases were promulgated in 1965 and revised in 1978.

Every hospital in which an infant is born shall obtain a blood sample from each infant prior to discharge. The physician or person legally responsible for signing the birth certificate of an infant born in a hospital shall arrange for the collection of this blood specimen. Should an infant not be born in a hospital, the person legally responsible for registering the birth shall arrange to have an authorized person take a blood specimen no later than the 5th day of life. These specimens must be mailed to the address supplied by the Division of Health within 24 hours of their collection.

A second blood sample shall be taken from every infant 2 to 4 weeks after birth, whether the infant was born in a hospital or elsewhere. These samples shall be submitted to the same address as the first samples. Before an infant is discharged from the hospital, the physician or other authorized person shall inform the parents or other responsible person or agency of this legal requirement. Every parent or legal guardian shall arrange to have a physician, hospital, public health nurse, or other authorized person administer this second blood test.

The parent or legal guardian of an infant who has a positive or questionable test result shall immediately refer the infant to a physician for further evaluation. This physician shall assume the responsibility for obtaining the final diagnosis and shall inform the Division of Health of this diagnosis within 14 days after referral.

VERMONT

In the State of Vermont, no law exists that mandates screening of newborns for any disorder. However, testing for phenylketonuria (PKU), hypothyroidism, and galactosemia for all newborns is done according to the provisions of a statewide system for screening under the auspices of the Vermont State Health Department.

All testing is voluntary and completed at one central laboratory within the state. Any positive or questionable test is followed up by notifying the attending physician and the health department. The department will then assist with further testing and treatment. The department is aided by an ad hoc committee consisting of the director of the Division of Medical Services, the chairman of the Department of Pediatrics, University of Vermont College of Medicine, a pediatric endocrinologist, a pathologist, and a specialist in developmental pediatrics. This ad hoc organization participates in the monitoring, consulting, and follow-up of the newborn screening program. At the present time, feasibility studies are being performed to determine whether to introduce regionalized newborn screening for metabolic disorders.

Those who are employed by the statewide project to test for PKU, hypothyroidism, and galactosemia assist volunteer groups within the state, such as the Vermont Tay-Sachs Disease Prevention Program.

VIRGINIA

At the present time the Commonwealth of Virginia has enacted two statutes concerning the screening for metabolic diseases. The first statute, Article 7 of the Health Laws, deals with testing for phenylketonuria (PKU); the second provides for the establishment of a screening program for sickle cell anemia and other genetically related diseases, genetic conditions, and metabolic diseases. The commonwealth has promulgated rules and regulations to implement the statute on PKU screening. Additionally, congenital hypothyroidism is screened in newborns, but formal regulations have not been promulgated.

Newborn Screening Statutes

Code of Virginia Sections 32.1-65 to 32.1-67 require the testing of every infant born in the commonwealth for PKU. Those persons attending the birth of a baby in a professional capacity, such as the physician, nurse or midwife, or, if none, the first attending physician, must ensure that the PKU test is performed. Should the result of a test indicate the possibility of PKU, the commissioner of health must notify the attending physician and produce or supply any further testing necessary to confirm or negate the diagnosis. All health care providers and administrators have a duty to inform the commissioner of every case of PKU. The Board of Health must then recommend procedures for the treatment of PKU and, in the case of 'medically indigent families', provide such treatment. The test is waived for any infant whose parents or guardians object in writing on religious grounds.

Administrative Regulations

The Rules and Regulations of the Board of Health, Governing the Detection and Control of Phenylketonuria, provide for the implementation and administration of the PKU laws. They clarify the respective duties of the Department of Health, physicians, nurses, midwives, hospital administrators and other persons in the commonwealth with regard to the screening, control, and treatment of PKU.

As stated in these regulations, the State Board of Health must: (1) provide for screening of all infants, except those exempt for religious reasons; (2) suggest methods of treatment for infants who have PKU; and (3) provide such treatment for infants of 'medically indigent families.' The state health commissioner, the chief executive officer of the State Department of Health, may act for the board when it is not in session. The director of the Bureau of Maternal and Child Health is responsible for the administration of the PKU testing, control, and treatment programs. The director, in addition, must make and receive the PKU reports and modifications. This includes informing the attending physician, or in situations where the attending physician is not identified, the local health director, in order to obtain more blood samples. When a presumptive positive diagnosis has been determined, the director must notify the attending physician and advise that the patient be hospitalized to confirm the diagnosis and begin early diet control to prevent mental retardation.

The regulations specifically outline the necessary timing of the test, the disposition of the blood specimens, the procedures for treatment, and penalties for noncompliance. The failure of any physician, nurse, or midwife to adhere to these rules constitutes grounds for revocation of his or her license or permit.

Other Relevant Laws or Regulations

Sections 32.1-68 and 32.1-69 declare that the commissioner, with cooperation of the local health directors, must establish a voluntary program for the testing of persons for sickle cell anemia, sickle cell trait, and other genetic diseases as the board may decide are necessary. The board shall periodically review the program to ascertain the proper age and method of screening for such conditions in light of changing medical technology.

This screening program includes provisions for education concerning the nature and treatment of sickle cell anemia and other genetically related diseases and metabolic disorders. In addition, a post-screening counseling program for any person diagnosed as having a certain condition is provided.

The result of any particular screening program will be sent to the individual's physician, if known, and either to the parents if the person screened is under 18 years of age, or to the individual himself if he is 18 years of age or older. These results may be used for research and statistical purposes; however, any records maintained must be strictly confidential and available only to the board, the commissioner or his agents, or to the local health director conducting the screening, unless explicit permission is obtained from the individual or from his parents.

WASHINGTON

Washington has one state law, recently amended, relating to phenylketonuria (PKU) and other preventable heritable disorders. Pursuant to this statute, the state has also issued regulations prescribing specific procedures for the testing for those diseases.

Newborn Screening Statutes

Revised Code of Washington Section 70.83 decrees that the Department of Social and Health Services shall require the testing of all newborn infants for PKU and other heritable diseases leading to mental retardation or physical defects before the infants are discharged from the hospital. No tests shall be performed on an infant whose parent or guardian objects for religious reasons.

The laboratories, hospital administrators, attending physicians, or any other person performing or requesting the performance of these tests shall inform the department of all positive PKU tests. The state board shall require, when it considers fitting, that positive cases for other heritable or metabolic disorders covered by this statute be reported to the department by those persons or agencies either performing or requesting the tests.

The department shall offer its services and facilities to the attending physician or, if no attending physician is identified, to the parents of the newborn child should the child be found to have a heritable or metabolic disorder. Within funding constraints, the services and facilities of this department and other cooperating state and local agencies shall be made available to the family and physician to prevent the onset of mental retardation or physical defects.

Administrative Regulations

Chapter 248-102 of the Washington Administrative Code names the parties responsible for the testing and the procedures to be employed. The administrators of all hospitals and maternity care facilities in Washington must send appropriate specimens and other necessary data for the laboratory tests for the detection of PKU and hypothyroidism to the health services division of the department. Specimens must be obtained from every infant prior to discharge from the institution or by the child's 10th day of life if not discharged. The specimen must be sent to the health services division laboratory not later than the close of the next working day.

The parents or guardian of each newborn must be informed by hospital personnel that the testing of their infant is to be administered in accordance with state law. The hospital staff must receive a signed statement from the parents or guardian should they refuse to allow their child to be tested because of their religious tenets and practices. This statement, or a copy of it, must be sent to the health services division of the department.

The department shall promptly notify the attending physician, or the family of an infant if no attending physician is known, in the event that the test on the infant suggests the presence of a disorder. The department shall then offer assistance to these parties in arranging further diagnostic studies, and financial support for these studies to qualified families.

The department and hospitals may make a reasonable charge to the parents of the newborn child for the testing procedure.

WEST VIRGINIA

At this time, the State of West Virginia has one law, recently amended in 1978, regarding the testing of infants for phenylketonuria (PKU) and hypothyroidism. Regulations have not yet been enacted pursuant to this law. At this time, PKU and hypothyroidism are being screened for in all newborn infants.

Newborn Screening Statutes

Sections 16-22-1 to 16-22-4 of the West Virginia Code authorize the State Department of Health to establish and implement a program to eradicate the mental retardation caused by PKU and hypothyroidism. To achieve this end, the department shall create and maintain facilities at its state laboratory for the analysis of specimens collected for the detection of these diseases.

The physician or other person attending a newborn child shall cause to have administered a test approved by the department for PKU and hypothyroidism. The test shall be analyzed by the state laboratory upon request of the physicians, hospital staff, medical personnel, or other persons attending the birth of a child. Any positive test for either of these diseases shall be promptly reported to the department by the director of the laboratory performing the test. In the event that a child is diagnosed for PKU or hypothyroidism, the department, in cooperation with other state departments and agencies and with the advice of attending physicians, shall provide medical, dietary, and related aid to the child.

A violation of the provisions of this article shall be a misdemeanor punishable by a fine of not less than \$25 or more than \$50. Violation of each provision shall constitute a separate offense.

Administrative Regulations

Although West Virginia has no formal regulations governing the implementation of the statute, the director of the State Department of Health issues memoranda explaining recommended procedures.

WISCONSIN

Chapter 160 of the Wisconsin Laws of 1977 mandated the creation of a council on infant health screening and the establishment of programs for the early detection of metabolic disorders in infants. Wisconsin also has statutes mandating a state plan for maternal and child health services and for assisting children with exceptional educational needs.

Newborn Screening Statutes

Wisconsin Statutes Section 15.197 (3p) created a council on infant health screening comprised of two persons chosen from the public who are not associated with health care provision or delivery, three physicians with expertise in metabolic disorders and one person appointed by the secretary of the Department of Health and Social Services. This council, part of the department, shall study and determine the feasibility of testing infants for the purpose of uncovering any metabolic disorders they may have. In addition, the council on infant health screening shall make recommendations to the department on the development and application of screening programs for infants.

Testing must be performed with the full informed consent of the parents or legal guardian and may be waived if they object on religious grounds. The Department of Health and Social Services shall decide which tests are to be performed and which regional laboratories may analyze them. In making this directive, the department may specify a single testing laboratory, several laboratories, or all public or private laboratories within the state. The laboratory or laboratories chosen must inform the attending physician of the test results; the physician in turn, must advise the parents or legal guardian. This information may not be disclosed unless the parent or guardian so consents and then may only be done so anonymously for the purpose of compiling statistical data by the department.

The department may also establish a program for the testing of an infant's urine to determine causes of metabolic disorders. State Law 146.02 (1M) provides that the department may develop methods of testing urine specimens. This testing is purely voluntary with no person required to participate in any program established under this subsection.

Administrative Regulations

Formal regulations for newborn screening have not been promulgated at this time.

WYOMING

The State of Wyoming has a law regarding newborn screening for metabolic diseases and regulations specifically outlining the provisions of this law.

Newborn Screening Statutes

Sections 35-4-801 to 802 of the Wyoming Statutes require the screening of infants for metabolic diseases. Every child born in Wyoming must be given tests, within 3 to 5 days after birth for normal children and within 5 to 8 days for prematurely born children, for the detection of inborn errors of metabolism. The specific tests to be performed shall be determined by a committee composed of the following: (a) the administrator of the Division of Health and Medical Services in the Department of Health and Social Services; (b) the president of the Wyoming State Medical Society; (c) a representative of the Wyoming State Pediatric Society; (d) a member designated by the Wyoming obstetric/gynecological society. Informed consent of the parents must be obtained prior to the testing. Should any parent or guardian object to the testing of his or her child, the child will be exempt from the mandatory examination prescribed by this law.

The department shall adopt necessary rules and regulations and disseminate them to all hospitals and physicians within Wyoming for implementation of the provisions of this law.

Administrative Regulations

The regulations authorized by Wyoming Statutes Sections 35-4-801 and 35-4-802 prescribe the mandatory testing of all newborn children for the detection of the following disorders: (a) phenylketonuria (PKU), (b) hypothyroidism, (c) galactosemia, (d) homocystinuria, (e) maple syrup urine disease, (f) sickle cell anemia, and (g) any other inborn error of metabolism for which testing may be later required by the committee.

If the child is born outside a hospital, the attending physician, midwife, or other person shall arrange to have the tests performed on the child. Every blood sample taken, whether outside or inside a hospital, shall be sent to the regional laboratory within 24 hours from the time that the sample was obtained from the child. A second blood sample for the follow-up PKU test should be obtained when the infant is approximately 2 weeks old and may be collected at a hospital laboratory, physician's office, or local public health facility. Hospitals must record the number of births and number of infants tested for the designated inborn errors of metabolism. This record must also include the number of infants not tested and the reason why no test was administered.

Positive or questionable results will be reported to the infant's physician and to the Division of Health and Medical Services.

The Division of Health and Medical Services will provide information pamphlets and consent forms on request. Written consent for screening must be obtained before any test is administered to an infant. Consent for the testing can be given by natural parents, either custodial parent or sole guardian, single parent having custody, prospective adoptive parents, or parent to whom the child's custody has been released. Any objection by the parent or guardian to the tests must be written. The child will then be exempt from such testing.

PUERTO RICO *

AMERICAN SAMOA *

GUAM *

MARIANA ISLANDS *

**TRUST TERRITORY OF
THE PACIFIC ISLANDS ***

VIRGIN ISLANDS *

APPENDICES

* At the present time there have been no laws or regulations enacted in the Commonwealth of Puerto Rico or any of the U.S. territories.

The State of Wyoming has a new regulation for the control of the disease known as "American Samoa" and for the control of the disease known as "American Samoa".

Regulation for the Control of the Disease Known as "American Samoa"

Section 1. The State of Wyoming hereby declares that the disease known as "American Samoa" is a communicable disease and that it is a disease of the type known as "American Samoa". The State of Wyoming hereby declares that the disease known as "American Samoa" is a communicable disease and that it is a disease of the type known as "American Samoa". The State of Wyoming hereby declares that the disease known as "American Samoa" is a communicable disease and that it is a disease of the type known as "American Samoa".

The State of Wyoming hereby declares that the disease known as "American Samoa" is a communicable disease and that it is a disease of the type known as "American Samoa".

Regulation for the Control of the Disease Known as "American Samoa"

The regulation for the control of the disease known as "American Samoa" is hereby declared to be a regulation for the control of the disease known as "American Samoa". The regulation for the control of the disease known as "American Samoa" is hereby declared to be a regulation for the control of the disease known as "American Samoa".

If the State of Wyoming has a communicable disease, the State of Wyoming shall declare that it is a communicable disease and that it is a disease of the type known as "American Samoa". The State of Wyoming shall declare that it is a communicable disease and that it is a disease of the type known as "American Samoa".

Provision of information for the control of the disease known as "American Samoa" shall be provided to the State of Wyoming and to the State of Wyoming.

The State of Wyoming and Medical Services will provide information for the control of the disease known as "American Samoa" and for the control of the disease known as "American Samoa". The State of Wyoming and Medical Services will provide information for the control of the disease known as "American Samoa" and for the control of the disease known as "American Samoa".

APPENDICES

APPENDIX A

SURVEY OF NEWBORN SCREENING PROGRAMS

The status of screening programs in the United States is dynamic and is constantly in the process of change. This report is a reflection of the information available to NCHGD as of July 31, 1980. For the most current information on screening programs for a particular state, please contact the Maternal and Child Health Director for that state.

	Phenylketonuria (PKU)	Hypothyroidism	Homocystinuria	Maple Syrup Urine Disease	Galactosemia	Tyrosinemia	Sickle Cell Anemia	Other	Metabolic Screening Advisory Committee
Alaska	•	•	•	•	•	•			
Alabama	•	•							
Arizona	•	•	•	•	•		•		•
Arkansas	•	•							
California	•	•			•		•		•
Colorado	•	•	•	•	•		•		
Connecticut	•	•			•				
Delaware	•	•	•	•	•	•			
District of Columbia*	•	•							•
Florida	•	•		•	•				•
Georgia	•	•	•	•	•	•	•		
Hawaii	•								
Idaho	•	•	•	•	•	•			
Illinois	•	•					•		
Indiana	•	•							•
Iowa	•	•		•	•				
Kansas	•	•					•		
Kentucky	•	•			•				
Louisiana	•	•					•		
Maine	•	•	•	•	•				
Maryland	•	•	•	•	•		•		•
Massachusetts	•	•	•	•	•		•	•	
Michigan	•	•							•
Minnesota	•	•			•				
Mississippi	•	•							
Missouri	•	•					•		
Montana	•	•	•	•	•	•			

See footnotes at end of table, p. 66

SURVEY OF NEWBORN SCREENING PROGRAMS—continued

	Phenylketonuria (PKU)	Hypothyroidism	Homocystinuria	Maple Syrup Urine Disease	Galactosemia	Tyrosinemia	Sickle Cell Anemia	Other	Metabolic Screening Advisory Committee
Nebraska	•	•							
Nevada	•	•	•	•	•	•			
New Hampshire	•	•							
New Jersey	•	•					•		
New Mexico	•	•	•	•	•		•		
New York	•	•	•	•	•		•	•	•
North Carolina	v				v	v	•		
North Dakota	•	•							
Ohio	•	•	•		•		•		
Oklahoma	•	•							
Oregon	•	•	•	•	•	•			
Pennsylvania	•	•							•
Rhode Island	•	v	v	v	v				
South Carolina	•	•							
South Dakota	•								
Tennessee	•	•							
Texas	•	•	•		•				
Utah	•	•			•				
Vermont	v	v			v				•
Virginia	•	•					•		
Washington	•	•							
West Virginia	•	•							
Wisconsin	•	•		•	•				•
Wyoming	•	•	•	•	•		•		•

v = voluntary, no statutory authority

• effective October 1980

¹ on request

² California genetic disease unit

³ Maryland Commission on Hereditary Disorders

⁴ tuberous sclerosis effective in 1986

⁵ Chronic Diseases Advisory Committee

⁶ histidinemia/adenosine deaminase deficiency

⁷ New York Birth Defects Institute

APPENDIX B

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Same

Same

APPENDIX C

MARIANA ISLANDS

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TRUST TERRITORY OF THE PACIFIC ISLANDS

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Same

CONNECTICUT

Information Bureau
State Capitol
Hartford, CT 06115
860-526-3770
(In state and area)

Same

DELAWARE

Legislative Council
P.O. Box 460
Dover, DE 19901
302-323-3343

Same

302-323-3343

DISTRICT OF COLUMBIA

Legislative Service Center
1000 Building, Suite 20
1000 F Street, NW
Washington, DC 20540
202-556-5575

Legislative Information Division
Capitol Building, Room 200
Washington, DC 20540
202-556-5575

Legislative Information Division

FLORIDA

House of Representatives
State Capitol, Room 1000
Tallahassee, FL 32304
904-488-3322
800-488-3322

House Information Office
State Capitol, Room 1000
Tallahassee, FL 32304
904-488-3322
800-488-3322

MAINE

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State Capitol, Room 100
Hartford, CT 06115
860-526-3770

MASSACHUSETTS

Legislative Information Center
Statehouse, Room 100 A
Boston, MA 02133
617-725-2000

WASHINGTON

Robert H. Lusk, M.D., Chief
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THE TERRITORY OF THE

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Territory of the Pacific Islands
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Office of the Director of Health Services
Territory of the Virgin Islands
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AMERICAN SAMSON

AMERICAN SAMSON

APPENDIX C

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House of Representatives
State Capitol
Montgomery, AL 36106
205-832-3554

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State Senate
State Capitol
Montgomery, AL 36106
205-832-6380

ALASKA

Legislative Affairs Agency
Pouch Y
Juneau, AK 99811
907-465-3800

ARIZONA

House Information Desk
1700 West Washington Street
House Wing
Phoenix, AZ 85007
602-255-4221
800-352-8484 ext. 4221
(in-state toll free)

Senate Information Desk
1700 West Washington Street
Senate Wing
Phoenix, AZ 85007
602-255-3559
800-352-8404 ext. 3559
(in-state toll free)

ARKANSAS

House Information Office
State Capitol, Room 2 East
Little Rock, AR 72201
501-371-3027

Senate Information Office
State Capitol, Room 320
Little Rock, AR 72201
501-375-6516

CALIFORNIA

Legislative Bill Room
1149 State Capitol
Sacramento, CA 95814
916-445-2323

COLORADO

Legislative Information
State Capitol
200 East Colfax Street
Denver, CO 80203
303-839-3055

CONNECTICUT

Information Room
State Capitol
Hartford, CT 06115
203-556-7050
800-842-2220
(in state toll free)

DELAWARE

Legislative Council
P.O. Box 1401
Legislative Hall
Dover, DE 19901
302-678-4114
800-282-8545
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DISTRICT OF COLUMBIA

Legislative Services Unit
District Building, Room 28
14th & E Streets, NW
Washington, DC 20004
202-724-8050

FLORIDA

Legislative Information Division
Capitol Building, Room 826
Tallahassee, FL 32304
904-488-4372
800-342-1827
(in-state toll free, April through June)

GEORGIA

House Information Office
State Capitol, Room 142A
Atlanta, GA 30334
404-656-5082
800-282-5800
(in-state toll free)

Senate Information Office
State Capitol, Room 122B
Atlanta, GA 30334
404-656-5097
800-282-5803
(in-state toll free)

HAWAII

Legislative Reference Bureau
State Capitol, Room 004
Honolulu, HI 96813
808-548-6237

IDAHO

Legislative Information Center
Statehouse, Room 301-A
Boise, ID 83720
208-384-2000

ILLINOIS

Legislative Information Center
705 William G. Stratton Building
Springfield, IL 62706
217-782-3944

INDIANA

Legislative Information
302 State House
Indianapolis, IN 46204
317-269-3747

IOWA

Legislative Service Bureau
Capitol Building
Des Moines, IA 50319
515-281-3566

KANSAS

Kansas State Library
Statehouse, 3rd Floor
Topeka, KS 66612
913-296-3296
800-432-3924
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KENTUCKY

Legislative Research Commission
State Capitol
Frankfort, KY 40601
502-564-8100
800-372-7194
(in-state toll free)

LOUISIANA

Louisiana Legislative Council
P.O. Box 44012
Capitol Station
Baton Rouge, LA 70804
504-342-2350

MAINE

Legislative Information
State House, Room 315
Augusta, ME 04333
207-289-3021

MARYLAND

Department of Legislative Reference
General Assembly of Maryland
90 State Circle
Annapolis, MD 21401
301-269-3201
(mid-January through mid-April)
301-269-2871
(mid-April through mid-January)
800-492-7122
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MASSACHUSETTS

Public Information Service
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Boston, MA 02108
617-727-7030

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Legislative Service Bureau
123 West Allegan, Suite 2
Lansing, MI 48913
517-373-0170

MINNESOTA

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State Capitol, Room 211
St. Paul, MN 55155
612-296-6646

Senate Index Office
State Capitol, Room 231
St. Paul, MN 55155
612-296-2887

MISSISSIPPI

Public Information
New Capitol
Jackson, MS 39203
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MISSOURI

State Library Information Service
308 East High Street
Jefferson City, MO 65102
314-751-3615

MONTANA

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Helena, MT 59601
406-449-3064

NEBRASKA

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State Capitol, Room 2018
Lincoln, NE 68509
402-471-2271
800-742-7456
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NEVADA

Legislative Council Bureau
Legislative Building
Capitol Complex
401 South Carson St.
Carson City, NV 89710
702-885-5637
800-992-0900
(in-state toll free, mid-January through mid-May, odd
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Concord, NH 03301
603-271-2239

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Office of Legislative Services
Division of Legislative Information and Research
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Trenton, NJ 08625
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800-792-8630
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Legislative Council Service
334 State Capitol Building
Sante Fe, NM 87503
505-827-3141

NEW YORK

Assembly Public Information Office
State Capitol, Room 148
Albany, NY 12248
518-472-6630

Secretary of the Senate
State Capitol, Room 321
Albany, NY 12247
518-455-2051

NORTH CAROLINA

Bill Status Information Desk
State Legislative Building
Raleigh, NC 27611
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NORTH DAKOTA

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State Capitol
Bismarck, ND 58505
701-224-2916
800-472-2678
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OHIO

Legislative Information
State House
Columbus, OH 43215
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800-282-0253
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OKLAHOMA

Legislative Reference Division
Oklahoma Department of Libraries
200 Northeast 18th Street
Oklahoma City, OK 73105
405-521-2502
800-522-8116
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OREGON

Legislative Information Administrative Committee
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Salem, OR 97310
503-378-8551
800-452-0290
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PENNSYLVANIA

Legislative Reference Bureau
P.O. Box 1127
Main Capitol Building
Harrisburg, PA 17120
717-787-4223

RHODE ISLAND

Rhode Island State Library
Rhode Island State House, Room 208
Providence, RI 02903
401-277-2473

SOUTH CAROLINA

Legislative Information Systems
State House
Columbia, SC 29202
803-758-5870
800-922-1539
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SOUTH DAKOTA

Legislative Research Council
Capitol Building
Pierre, SD 57501
605-773-3251
800-592-1865
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TENNESSEE

Legislative Services
State Capitol, Ground Floor
Nashville, TN 37219
615-741-3511

TEXAS

House Journal Clerk
House of Representatives
P.O. Box 2910
Austin, TX 78711
512-475-6294

(January through May, even numbered years)
Legislative Information 512-475-3026
(January through May, odd numbered years)
800-252-9693

(in-state toll free, January through May,
odd numbered years)

UTAH

Office of Legislative Research
State Capitol, Room 436
Salt Lake City, UT 84114
801-533-5481

VERMONT

Sergeant-at-Arms Office
State Capitol Building
State House
Montpelier, VT 05602
802-828-2228

VIRGINIA

Legislative Information
State Capitol Building
Richmond, VA 23219
804-786-6530

WASHINGTON

Legislative Bill Room
Legislative Building
Olympia, WA 98504
206-753-7573
800-562-6000

(in-state toll free, January through March)

WEST VIRGINIA

Legislative Public Information Office
153 Main Unit
State Capitol Building
Charleston, WV 25305
304-348-8905
800-642-8650
(in-state toll free)

WISCONSIN

Legislative Reference Bureau
State Capitol, Room 201 North
Madison, WI 53702
608-266-0341

WYOMING

Legislative Service Office
Capitol Building, Room 213
Cheyenne, WY 82002
307-777-7881

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